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ABSTRACT

The participant's manual contains training materials for a national teleconference on the history and philosophy of the independent living movement for agency personnel. Preliminary materials include the conference agenda, background information about the trainers, and organizational information on Independent Living Research Utilization and the National Council on Independent Living. The first section discusses a paradigm shift and includes a chart contrasting the paradigm based on the medical model, rehabilitation, community assistance, charity paradigm with the paradigm based on independent living, disability rights, disability culture, and disability pride. Information on the Department of Education's Office of Special Education and Rehabilitative Services (OSERS), especially the Independent Living Branch, is followed by a section titled "History of Independent Living" by Gina McDonald and Mike Oxford. Next is the text of "Freedom of Movement: Independent Living History and Philosophy" by Steven E. Brown. Topics covered include the independent living philosophy, the case of Franklin Delano Roosevelt, the New York League of the Physically Handicapped, World War II Veterans, a case study emphasizing freedom of movement, accessibility at the University of Illinois, polio and Ed Roberts, Section 504 and vocational rehabilitation, the 1970s, independence in the 1980s and 1990s, and independent living in 2000. An appendix lists dates in independent living history. (Contains 30 references.) (DB)

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IL NET Presents...

ED 479 821

Teleconference:
IL 201:
History & Philosophy of the Independent Living Movement

August 8, 2002

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Expanding the Power of the Independent Living Movement

IL NET

an ILRU/NCIL National Training and Technical Assistance Project

Expanding the Power of the Independent Living Movement

IL 201:
HISTORY & PHILOSOPHY OF THE INDEPENDENT LIVING MOVEMENT

A National Teleconference

Participant's Manual

August 8, 2002

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IL 201:
History & Philosophy of the Independent Living Movement
A National Teleconference

Participant's Manual
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IL 201:
History and Philosophy in the Independent Living Movement

AGENDA

Welcome and Introduction

History of the First CIL

Q&A

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The 1992 Reauthorization of the Rehabilitation Act

Independent Living Philosophy

- Consumer Control
- Self-help and Self-advocacy
- Peer Relationships and Role Models
- Equal Access

Q&A

Wrap-up

ABOUT THE TRAINER

Julia Sain has been working at Programs for Accessible Living in Charlotte, North Carolina since 1984. Currently she is the Executive Director. Over the years, Julia has performed many training activities for consumers, business leaders, government personnel, human resource professionals, and CIL staff and board members. She founded a local chapter of the Registry of Interpreters for the Deaf (RID). She is currently on the North Carolina SILC as the CIL representative. Julia also serves as a member of NCIL's Rehabilitation Act Subcommittee.

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ABOUT ILRU

The Independent Living Research Utilization (ILRU) Program was established in 1977 to serve as a national center for information, training, research, and technical assistance for independent living. In the mid-1980's, it began conducting management training programs for executive directors and middle managers of independent living centers in the U.S.

ILRU has developed an extensive set of resource materials on various aspects of independent living, including a comprehensive directory of programs providing independent living services in the U.S. and Canada.

ILRU is a program of TIRR, a nationally recognized, free-standing rehabilitation facility for persons with physical disabilities. TIRR is part of TIRR Systems, a not-for-profit corporation dedicated to providing a continuum of services to individuals with disabilities. Since 1959, TIRR has provided patient care, education, and research to promote the integration of people with physical and cognitive disabilities into all aspects of community living.

ABOUT NCIL

Founded in 1982, the National Council on Independent Living is a membership organization representing independent living centers and individuals with disabilities. NCIL has been instrumental in efforts to standardize requirements for consumer control in management and delivery of services provided through federally-funded independent living centers.

Until 1992, NCIL's efforts to foster consumer control and direction in independent living services through changes in federal legislation and regulations were coordinated through an extensive network and involvement of volunteers from independent living centers and other organizations around the country. Since 1992, NCIL has had a national office in Arlington, Virginia, just minutes by subway or car from the major centers of government in Washington, D.C. While NCIL continues to rely on the commitment and dedication of volunteers from around the country, the establishment of a national office with staff and other resources has strengthened its capacity to serve as the voice for independent living in matters of critical importance in eliminating discrimination and unequal treatment based on disability.

Today, NCIL is a strong voice for independent living in our nation's capital. With your participation, NCIL can deliver the message of independent living to even more people who are charged with the important responsibility of making laws and creating programs designed to assure equal rights for all.

ABOUT THE IL NET

This training program is sponsored by the IL NET, a collaborative project of the Independent Living Research Utilization (ILRU) of Houston and the National Council on Independent Living (NCIL).

The IL NET is a national training and technical assistance project working to strengthen the independent living movement by supporting Centers for Independent Living (CILs) and Statewide Independent Living Councils (SILCs).

IL NET activities include workshops, national teleconferences, technical assistance, on-line information, training materials, fact sheets, and other resource materials on operating, managing, and evaluating centers and SILCs.

The mission of the IL NET is to assist in building strong and effective CILs and SILCs which are led and staffed by people who practice the independent living philosophy.

The IL NET operates with these objectives:

- Assist CILs and SILCs in managing effective organizations by providing a continuum of information, training, and technical assistance.
- Assist CILs and SILCs to become strong community advocates/change agents by providing a continuum of information, training, and technical assistance.
- Assist CILs and SILCs to develop strong, consumer-responsive services by providing a continuum of information, training, and technical assistance.

The Paradigm Shift

The "Independent Living Paradigm"

	MEDICAL MODEL, REHABILITATION, COMMUNITY ASSISTANCE (service delivery system), CHARITY PARADIGM	INDEPENDENT LIVING, DISABILITY RIGHTS, DISABILITY CULTURE, DISABILITY PRIDE PARADIGM
Definition of the problem	physical or mental impairment; lack of vocational skill, lack of education, lack of socio-economic status, lack of political and cultural skills	dependence upon professionals, family members and others; hostile attitudes and environments; lack of legal protection; lack of recognition of inherent worth of people with disabilities (stereotypes).
Locus of the problem	in the individual (individual is "broken" or "sick" and needs to "fixed" or "cured" to "fit" into society)	in the socio-economic, political, and cultural environment; in the physical environment; in the medical, rehabilitation, service delivery or charity processes themselves (dependency-creating).
Solution to the problem	professional interventions; treatment; "case management" or volunteer work based on pity and related attitudes	1) advocacy; 2) barrier removal; 3) consumer-control over options and services; 4) peer role models and leaders; 5) self-help -- all leading to equitable socio-economic, cultural and political options.
Social role of person	individual with a disability is a "patient," "client," or recipient of charity; in many situations, the social role is non-existent	family and community members; "consumers" or "customers," "users" of services and products -- just like anyone else.
Who controls	professional	person with the disability or his/her choice of another individual or group.
Desired outcomes	maximum self-care (or "ADL" -- activities of daily living as used in occupational therapeutic sense); gainful employment in the vocational rehabilitation system; no "social misfits" or no "manipulative clients"	independence through control over **ACCEPTABLE** options for living in an integrated community of choice; pride in unique talents and attributes of each individual; positive disability identity.

This paradigm was originally developed in 1978 by Gerben DeJong, now with the National Rehabilitation Hospital in Washington, D.C. It has been modified since then by Maggie Shreve, an organization development consultant working in the field of disability rights out of Chicago, and Steve Brown, a disability policy consultant and principle co-owner of the Institute for Disability Culture in Santa Fe, New Mexico.

1992 REAUTHORIZATION OF THE 1973 REHAB ACT

- → SPECIFIED TERMINOLOGY
- → ESTABLISHED ASSURANCES AND STANDARDS FOR WHO WE WOULD BE AND WHAT WE WOULD DO
- → INCREASED FUNDING FOR MORE CENTERS
- → SET UP STATEWIDE INDEPENDENT LIVING COUNCILS (SILC)
- → PROVIDED DIRECT FUNDING TO CIL'S

Who's Who at the U.S. Department of Education

ILRU Resource Files: Information for the independent living community from the IL Net

Funds for programs authorized under Title VII of the Rehabilitation Act, including centers for independent living, are administered by the Rehabilitation Services Administration, which is a program component of the Office of Special Education and Rehabilitative Services (OSERS). OSERS is part of the U.S. Department of Education.

To help you keep track of the players, the offices they represent and their relationship to one another, the IL Net has compiled this list of Who's Who at the Department of Education. Program descriptions and staff biographies were taken from the Department of Education Website, www.ed.gov.

Rod Paige
Secretary of Education

Secretary Paige became the superintendent of schools of Houston Independent School District (HISD) in 1994. As superintendent, Secretary Paige created the Peer Examination, Evaluation, and Redesign (PEER) program, which solicits recommendations from business and community professionals for strengthening school support services and programs. He launched a system of charter schools that have broad authority in decisions regarding staffing, textbooks, and materials. He saw to it that HISD paid teachers salaries competitive with those offered by other large Texas school districts. Secretary Paige made HISD the first school district in the state to institute performance contracts modeled on those in the private sector, whereby senior staff members' continued employment with HISD is based on their performance. He also introduced teacher incentive pay, which rewards teachers for outstanding performance and creative solutions to educational problems.

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Robert H. Pasternack
Assistant Secretary
OSERS

Robert H. Pasternack is the assistant secretary for special education and rehabilitative services. OSERS assists in the education of disabled children and the rehabilitation of disabled adults and conducts research to improve the lives of disabled persons regardless of age. Since 1998 Pasternack has been New Mexico state director of special education. Previously, he was chief executive officer of Casa de Corazon, a children's mental health center in Taos, N.M. He also served as superintendent of New Mexico Boys' School in Springer. Pasternack received a Ph.D. in special education from the University of New Mexico in Albuquerque and a master's degree in guidance and counseling from New Mexico Highlands University in Las Vegas. He is certified as a special education teacher, an educational diagnostician, and as a school psychologist.

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Joanne M. Wilson
Commissioner
RSA

Joanne M. Wilson is the commissioner of the Rehabilitation Services Administration (RSA), in the Office of Special Education and Rehabilitative Services. The Rehabilitation Services Administration (RSA) oversees programs that help individuals with physical or mental disabilities to obtain employment through the provision of such supports as counseling, medical and psychological services, job training, and other individualized services. RSA's major formula grant program provides funds to state vocational rehabilitation agencies to provide employment-related services for individuals with disabilities, giving priority to individuals who are severely disabled. Since 1985 Wilson has been director of the Louisiana Center for the Blind, which she founded as the state's first adult orientation and adjustment training facility and independent living center for the blind. She has also served as a consultant to the Connecticut Board of Education and Services for the Blind, the New Jersey Orientation and Adjustment Center for the Blind, and the New York Commission for the Blind. Wilson has a master's degree in guidance and counseling and administration from Iowa State University. She was an elementary school teacher in Ames, Iowa, where she taught both blind and sighted children, and a continuing education instructor at Louisiana Tech University.

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The Special Projects Division (SPD) develops and interpret regulations, policies, and guidelines and coordinates and provides direction for RSA program activities designed to expand and improve rehabilitation services for persons with disabilities. SPD staff develop appropriate mechanisms to ensure that successful outcomes of such activities are integrated into the practices of rehabilitation agencies. Division staff also administer special projects for Supported Employment, migrant and seasonal farm workers and their families, Projects With Industry (PWI), recreation projects, and all programs related to Independent Living.

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James Billy
Chief
Independent Living Branch

Staff in the Independent Living Branch administer IL programs under Title VII of the Rehabilitation Act Living Programs. They develop and interpret regulations and policies for Independent Living (IL) programs; develop guidelines and provide technical assistance to applicants for and grantees of Independent Living programs; provide guidance and technical assistance to Regional Offices staff for State agencies and Centers for Independent Living projects; establish data gathering methods and monitoring guides for IL programs; maintain liaison with consumer organizations to foster development of independent living services; collaborate with the National Institute on Disability and Rehabilitation Research (NIDRR) concerning research findings and their application to enhance the IL options for persons with significant disabilities; and disseminate findings and effective practices resulting from IL program activities to other RSA offices, Regional Office staff, State agencies, Centers for Independent Living and other public and private agencies and practitioners.

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Steven James Tingus
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NIDRR

As director of the National Institute on Disability and Rehabilitation Research (NIDRR), Tingus will serve as chief advisor to Assistant Secretary for Special Education and Rehabilitative Services Robert Pasternack and direct research programs and activities related to maximizing employment and independent living opportunities for disabled individuals of all ages. In addition, Tingus will manage all NIDRR activities. His responsibilities will include preparing a long-range plan for rehabilitation research; directing funding and resources for research and training centers; evaluating current and future operating programs; and disseminating new research related to disabilities and effective rehabilitation policies and practices. Prior to joining the Education Department, Tingus served as director of resource development and public policy director for assistive technology at the California Foundation for Independent Living Centers. In that capacity, Tingus developed and implemented model policies and activities to broaden access to assistive technology for persons with disabilities to help them live independent and productive lives. From 1995-1998, Tingus served as health care policy analyst in the Office of Long Term Care at the California Department of Health Services. Tingus earned his master of science degree in physiology from the University of California, Davis, in 1990 and has done work toward his doctoral degree in physiology.

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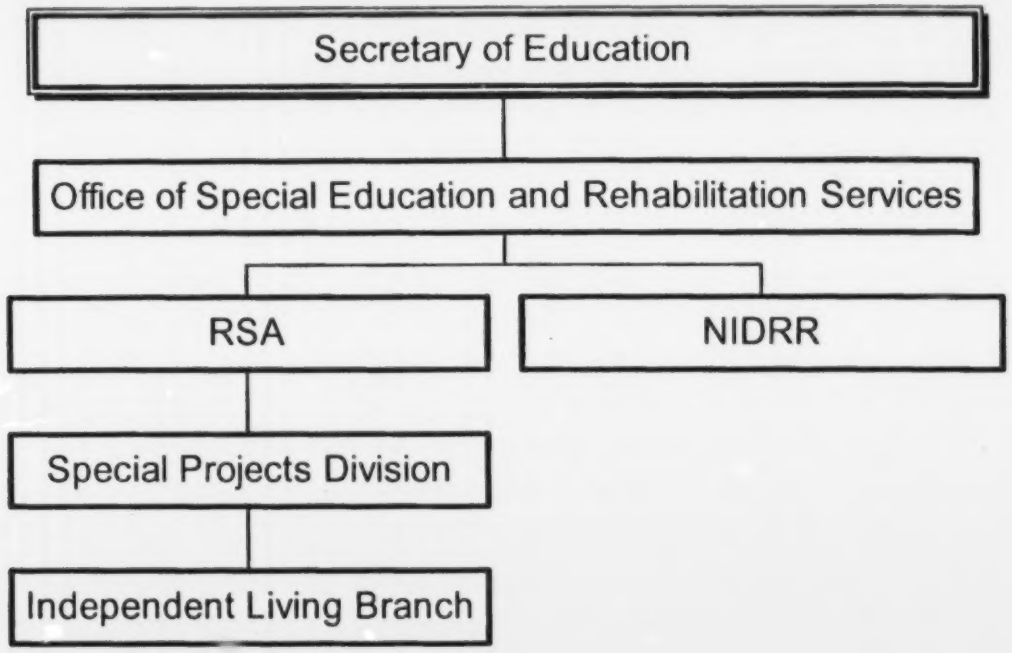
Organizational Chart



A more detailed organizational chart is available at
http://www.ed.gov/about/offices.jsp

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History of Independent Living

by Gina McDonald and Mike Oxford

History of Independent Living
by Gina McDonald and Mike Oxford

This account of the history of independent living stems from a philosophy which states that people with disabilities should have the same civil rights, options, and control over choices in their own lives as do people without disabilities.

The history of independent living is closely tied to the civil rights struggles of the 1950s and 1960s among African Americans. Basic issues--disgraceful treatment based on bigotry and erroneous stereotypes in housing, education, transportation, and employment --and the strategies and tactics are very similar. This history and its driving philosophy also have much in common with other political and social movements of the country in the late 1960s and early 1970s. There were at least five movements that influenced the disability rights movement.

Social Movements

The first social movement was deinstitutionalization, an attempt to move people, primarily those with developmental disabilities, out of institutions and back into their home communities. This movement was led by providers and parents of people with developmental disabilities and was based on the principle of "normalization" developed by Wolf Wolfensberger, a sociologist from Canada. His theory was that people with developmental disabilities should live in the most "normal" setting possible if they were to expected to behave "normally." Other changes occurred in nursing homes where young people with many types of disabilities were warehoused for lack of "better" alternatives (Wolfensberger, 1972).

The next movement to influence disability rights was the civil rights movement. Although people with disabilities were not included as a protected class under the Civil Rights Act, it was a reality that people could achieve rights, at least in law, as a class. Watching the courage of Rosa Parks as she defiantly rode in the front of a public bus, people with disabilities realized the more immediate challenge of even getting on the bus.

The "self-help" movement, which really began in the 1950s with the founding of Alcoholics Anonymous, came into its own in the 1970s. Many self-help books were published and support groups flourished. Self-help and peer support are recognized as key points in independent living philosophy. According to this tenet, people with similar disabilities are believed to be more likely to assist and to understand each other than individuals who do not share experience with similar disability.

Demedicalization was a movement that began to look at more holistic approaches to health care. There was a move toward "demystification" of the medical community. Thus, another cornerstone of independent living philosophy became the shift away from

the authoritarian medical model to a paradigm of individual empowerment and responsibility for defining and meeting one's own needs.

Consumerism, the last movement to be described here, was one in which consumers began to question product reliability and price. Ralph Nader was the most outspoken advocate for this movement, and his staff and followers came to be known as "Nader's Raiders." Perhaps most fundamental to independent living philosophy today is the idea of control by consumers of goods and services over the choices and options available to them.

The independent living paradigm, developed by Gerben DeJong in the late 1970s (DeJong, 1979), proposed a shift from the medical model to the independent living model. As with the movements described above, this theory located problems or "deficiencies" in the society, not the individual. People with disabilities no longer saw themselves as broken or sick, certainly not in need of repair. Issues such as social and attitudinal barriers were the real problems facing people with disabilities. The answers were to be found in changing and "fixing" society, not people with disabilities. Most important, decisions must be made by the individual, not by the medical or rehabilitation professional.

Using these principles, people began to view themselves as powerful and self-directed as opposed to passive victims, objects of charity, cripples, or not-whole. Disability began to be seen as a natural, not uncommon, experience in life, not a tragedy.

ADAPT

Wade Blank began his lifelong struggle in civil rights activism with Dr. Martin Luther King, Jr. in Selma, Alabama. It was during this period that he learned about the stark oppression which occurred against people considered to be outside the "mainstream" of our "civilized" society. By 1971, Wade was working in a nursing facility, Heritage House, trying to improve the quality of life of some of the younger residents. These efforts, including taking some of the residents to a Grateful Dead concert, ultimately failed. Institutional services and living arrangements were at odds with the pursuit of personal liberties and life with dignity.

In 1974, Wade founded the Atlantis Community, a model for community-based, consumer-controlled, independent living. The Atlantis Community provided personal assistance services primarily under the control of the consumer within a community setting. The first consumers of the Atlantis Community were some of the young residents "freed" from Heritage House by Wade (after he had been fired).
Initially, Wade provided personal assistance services to nine people by himself for no pay so that these individuals could integrate into society and live lives of liberty and dignity. In 1978, Wade and Atlantis realized that access to public transportation was a necessity if people with disabilities were to live independently in the community. This was the year that American Disabled for Accessible Public Transit (ADAPT) was founded.

On July 5-6, 1978, Wade and nineteen disabled activists held a public transit bus "hostage" on the corner of Broadway and Colfax in Denver, Colorado. ADAPT

eventually mushroomed into the nation's first grassroots, disability rights, activist organization.

In the spring of 1990, the Secretary of Transportation, Sam Skinner, finally issued regulations mandating lifts on buses. These regulations implemented a law passed in 1970-the Urban Mass Transit Act-which required lifts on new buses. The transit industry had successfully blocked implementation of this part of the law for twenty years, until ADAPT changed their minds and the minds of the nation. In 1990, after passage of the Americans With Disabilities Act (ADA), ADAPT shifted its vision toward a national system of community-based personal assistance services and the end of the apartheid-type system of segregating people with disabilities by imprisoning them in institutions against their will. The acronym ADAPT became "American Disabled for Attendant Programs Today." The fight for a national policy of attendant services and the end of institutionalization continues to this day.

Wade Blank died on February 15, 1993, while unsuccessfully attempting to rescue his son from drowning in the ocean. Wade and Ed Roberts live on in many hearts and in the continuing struggle for the rights of people with disabilities.

These lives of these two leaders in the disability rights movement, Ed Roberts and Wade Blank, provide poignant examples of the modern history, philosophy, and evolution of independent living in the United States. To complete this rough sketch of the history of independent living, a look must be taken at the various pieces of legislation concerning the rights of people with disabilities, with a particular emphasis on the original "bible" of civil rights for people with disabilities, the Rehabilitation Act of 1973.

Civil Rights Laws

Before turning to the Rehabilitation Act, a chronological listing and brief description of important federal civil rights laws affecting people with disabilities is in order.

1964 Civil Rights Act: prohibits discrimination on the basis of race, religion, ethnicity, national origin, and creed -- later, gender was added as a protected class.

1968 Architectural Barriers Act: prohibits architectural barriers in all federally owned or leased buildings.

1970 Urban Mass Transit Act: requires that all new mass transit vehicles be equipped with wheelchair lifts. As mentioned earlier, it was twenty years, primarily because of machinations of the American Public Transit Association (APTA), before the part of the law requiring wheelchair lifts was implemented.

1973 Rehabilitation Act: particularly Title V, Sections 501, 503, and 504, prohibits discrimination in federal programs and services and all other programs or services receiving federal funding.

1975 Developmental Disabilities Bill of Rights Act: among other things, establishes Protection and Advocacy services (P & A).

1975 Education of All Handicapped Children Act (PL 94-142): requires free, appropriate public education in the least restrictive environment possible for children with disabilities. This law is now called the Individuals with Disabilities Education Act (IDEA).

1978 Amendments to the Rehabilitation Act: provides for consumer-controlled centers for independent living.

1983 Amendments to the Rehabilitation Act: provides for the Client Assistance Program (CAP), an advocacy program for consumers of rehabilitation and independent living services.

1985 Mental Illness Bill of Rights Act: requires protection and advocacy services (P & A) for people with mental illness.

1988 Civil Rights Restoration Act: counteracts bad case law by clarifying Congress' original intention that under the Rehabilitation Act, discrimination in AN-Y program or service that is a part of an entity receiving federal funding --not just the part which actually and directly receives the funding --is illegal.

1988 Air Carrier Access Act: prohibits discrimination on the basis of disability in air travel and provides for equal access to air transportation services.

1988 Fair Housing Amendments Act: prohibits discrimination in housing against people with disabilities and families with children. Also provides for architectural accessibility of certain new housing units, renovation of existing units, and accessibility modifications at the renter's expense.

1990 Americans with Disabilities Act: provides comprehensive civil rights protection for people with disabilities; closely modeled after the Civil Rights Act and the Section 504 of Title V of the Rehabilitation Act and its regulations.

The modern history of civil rights for people with disabilities is three decades old. A key piece of this decades-long process is the story of how the Rehabilitation Act of 1973 was finally passed and then implemented. It is the story of the first organized disability rights protest.

The Rehabilitation Act of 1973

In 1972, Congress passed a rehabilitation bill that independent living activists cheered. President Richard Nixon's veto prevented this bill from becoming law. During the era of political activity at the end of the Vietnam War, Nixon's veto was not taken lying down by disability activists who launched fierce protests across the country. In New York City early leader for disability fights, Judy Heumann, staged a sit-in on Madison Avenue with eighty other activists.

Traffic was stopped. After a flood of angry letters and protests, in September 1973, Congress overrode Nixon's veto and the Rehabilitation Act of 1973 finally became law. Passage of this pivotal law was the beginning of the ongoing fight for implementation and revision of the law according to the vision of independent living advocates and disability rights activists. Key language in the Rehabilitation Act, found in Section 504 of Title V, states that:

No otherwise qualified handicapped individual in the United States shall, solely by reason of his handicap, be excluded from the participation in, be denied the benefits of, or be subjected to discrimination under any program or activity receiving federal financial assistance.

Advocates realized that this new law would need regulations in order to be implemented and enforced. By 1977, Presidents Nixon and Ford had come and gone. Jimmy Carter had-become president and had appointed Joseph Califano his Secretary of Health, Education and Welfare (HEW). Califano refused to issue regulations and was given an ultimatum and deadline of April 4, 1977. April 4 went by with no regulations and no word from Califano.

On April 5, demonstrations by people with disabilities took place in ten cities across the country. By the end of the day, demonstrations in nine cities were over. In one city, San Francisco, protesters refused to disband.

Demonstrators, more than 150 people with disabilities, had taken over the federal office building and refused to leave. They stayed until May 1. Califano had issued regulations by April 28, but the protesters stayed until they had reviewed the regulations and approved of them.

The lesson is a fairly simple one. As Martin Luther King said,

> *It is an historical fact that the privileged groups seldom give up their privileges voluntarily. Individuals may see the moral light and voluntarily give up their unjust posture, but, as we are reminded, groups tend to be more immoral than individuals. We know, through painful experience that freedom is never voluntarily given by the oppressor, it must be demanded by the oppressed.*

Leaders in the Independent Living Movement

The history of the independent living movement is not complete without mention of some other leaders who continue to make substantial contributions to the movement and to the rights and empowerment of people with disabilities.

Max Starkloff, Charlie Carr, and Marca Bristo founded the National Council on Independent Living (NCEL) in 1980. NCEL is one of the only national organizations that is consumer-controlled and promotes the rights and empowerment of people with disabilities.

Justin Dart played a prominent role in the fight for passage of the Americans with Disabilities Act, and is seen by many as the spiritual leader of the movement today.

Lex Frieden is co-founder of ELRU Program. As director of the National Council on Disability, he directed preparation of the original ADA legislation and its introduction in Congress.

Liz Savage and Pat Wright are considered to be the "mothers of the ADA." They led the consumer fight for the passage of the ADA.

There are countless other people who have and continue to make substantial contributions to the independent living movement.

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FREEDOM OF MOVEMENT

INDEPENDENT LIVING HISTORY AND PHILOSOPHY

by Steven E. Brown
Institute on Disability Culture

ILRU bookshelf series
Publications for Independent Living

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INTRODUCTION

Can Independent Living (IL) history be separated from IL philosophy?

When I began to write this monograph I thought I would start with the students at the University of Illinois. But as I learned more about that program I realized it may not have existed without World War II veterans who needed an education. How, I then wondered, does one distinguish the impact of World War II on disability history from Franklin Delano Roosevelt (FDR), a President who used a wheelchair and served as commander-in-chief for most of that war? So I chose to begin the history with FDR.

If someone thinks that the disability rights movement began in 1990 with the passage of the Americans with Disabilities Act or the 1970s with the first centers for independent living, how would I explain why I chose to begin with someone who predates those events by several decades. The solution seemed to be using a general explanation of IL philosophy as a preface to a beginning discussion of the history.

One of the difficulties, as well as one of the pleasures of writing this monograph, is that our history is so fragmented. I know of nowhere else where all the information in this monograph is tied together. As a historian assembling this monograph, I'm excited. But as an advocate with a disability, it is frustrating to realize how scattered our historical information remains.

Much more work needs to be done before we have even the beginnings of a coherent, let alone comprehensive, history of our movement. But as always, we must begin somewhere, and therefore I choose to begin with a description of IL philosophy I wrote several years ago that still seems appropriate.

INDEPENDENT LIVING PHILOSOPHY

Several fundamental beliefs have been combined to establish the foundation on which to construct an independent living philosophy. These premises include the notion that each individual is different and unique; that people with disabilities are the most knowledgeable experts about our own needs and issues; and that programs serving disabled people should be designed to serve all disability groups.

Just as every person is different from each other, so too are disabling conditions. This applies not only to the differences between differing disabilities, such as deafness and mental illness and paralysis, but also to individual differences within each disability category.

For example, each person with a disability who uses a wheelchair is unique. Some people using wheelchairs are paralyzed, others are not. Some use their feet, but not their arms; others their arms, but not feet. Some wheelchair users use their breath to move their chair, others their head.

The point is that just as each wheelchair must be designed to fit the individual needs of the person using that mobility aid, so too must every other adaptation be adjusted to the individual. To make this equation just a little more complicated, disabling conditions, like people, are often dynamic, not static. So the results of the disabling condition itself are often changing and, to return to the example of wheelchairs, an individual who uses a certain kind of wheelchair one year may need a different kind the next so that there is a constant adjustment to the changing conditions of the disability or, even more salient, to the changing conditions of life.

Every individual and every disability condition is different, therefore every individual with a disabling condition is unique. People who are most familiar with disabilities, that is, those who have them, are best-suited to discuss the needs and issues of people with disabilities. This is not to say that a person without a disability is incapable of knowing, understanding, or empathizing with what it is like to have a disability. But it is to say that it's much more likely for a person with a disability to possess these characteristics.

The notion of one person with a disability having some understanding of another person with a disability forms a primary underpinning of independent living philosophy, which is the concept of peer support. In independent living terms, a peer is someone with a disability who is a role model and/or support person for another person with a disability. Translated to other movements, it is the same concept that drives Alcoholics Anonymous and all the other anonymous self-help programs. It drives the concept of groups as institutionalized as the YW and MCAs and of groups as historically radical as the Black Panthers.

The ideas of peer support and people with disabilities knowing what is best for ourselves leads directly into the concept of people with disabilities running our own

programs. That is why many independent living programs require boards of directors to have at least a majority of their members be people with disabilities.

But there is another very important reason for people with disabilities managing their own programs. This is the whole issue of empowerment. For someone who is not empowered, and as a group people with disabilities are not, it is of utmost importance that power positions, such as boards of directors, can be perceived as role models.

A useful analogy is that of Women's Resource Centers. Few people would argue that men should run programs for women. Men are not women and no matter how hard we may try there are just some things that men will never be able to have in common with women. So it makes sense for women to be the primary participants in running programs designed for women. Now just plug in the phrase "people with disabilities" for women in the preceding three sentences.

Substitute "nondisabled people" for men in the same sentences. See if it makes sense. If it does, then one has just agreed with one of the basic philosophies known in independent living jargon as "consumer control," that is people with disabilities as the consumers of programs designed for them also ought to be the principal players involved in their direction and management.

The final philosophical framework of independent living programs is that they should be designed to serve all disability groups. This may be the most controversial of the independent living beliefs. Many population groups--including people with hearing impairments, visual impairments, brain injuries, mental retardation, psychiatric disabilities, and probably any other disability demographic population identified--have stated at one time or another that separate services are necessary for their specific conditions.

Proponents of the independent living philosophy known as cross-disability counter that all people with disabilities are oppressed and that there is little difference in the big picture of the discrimination against people with disabilities. To paraphrase a well-known quote: oppression is oppression is oppression.

Cross-disability advocates will agree that there may be different tools to use toward the overarching goal of independence. For example, a deaf person may need sign language for communication and a person with a head injury may need a tape recorded reminder to do a task and a person whose legs don't work well may need a wheelchair. But beyond the necessity of different tools is the common goal of an opportunity for full participation in the cultural, social, economic and political aspects of our society.

The driving beliefs of independent living philosophy are a recognition that each person with a disability, like each person, is unique; that because of this uniqueness people with disabilities are in the best position to guide, direct, and control their own programs; and that because all people with disabilities are oppressed, independent

living programs need to be designed to ensure equal social, cultural, economic, and political opportunities for all disability groups. (Brown, *Independent Living* 2-5)

In the next section, we'll look at the life of FDR to consider if he might be called a predecessor of the disability rights movement. To put it another way, could FDR have been considered, "a peer. . . someone with a disability who is a role model and/or support person for another person with a disability."

WAS HE OR WASN'T HE?

FDR grew up in a wealthy, civic-minded family in New York State. A personable and vigorous young man, he followed the path of his cousin, President Theodore Roosevelt, first in joining the Navy, then in quickly becoming a successful politician. Unlike his older cousin, FDR's first Presidential election was a losing one as the Vice-Presidential candidate of the 1920 Democratic slate.

Shortly thereafter, his political future unclear, he contracted polio. Both his legs became permanently paralyzed and he became a wheelchair-user.

FDR's wealth and contacts enabled him to pursue physical rehabilitation anywhere he chose. He selected Warm Springs, Georgia. He poured much of his energy and wealth into building a modern rehabilitation facility there.

For many years, historical accounts of FDR's polio treated it as a brief and isolated incident in his life which probably proved to his political benefit. These narratives contend that voters felt distanced from the healthy and wealthy FDR. But polio became a great equalizer. It demonstrated that even someone with FDR's breeding and riches could be brought down a notch or two and in so doing would become more appealing to the voters who would elect him. In addition, FDR turned to his wife Eleanor, whose compassion is now legendary, to keep him in touch with everyday issues and the average citizen. Finally, his long recovery enabled him to write many letters, entertain visitors, and make numerous contacts in a concerted effort to reenter the political scene. He did so with great success. FDR was elected governor of New York in the latter part of the 1920s, setting the stage for his quest to become President.

Hugh Gregory Gallagher eloquently opposes this traditional narrative in his groundbreaking study FDR's Splendid Deception. He argues that this typical portrayal of a short bout with polio contains little understanding of disability and its long-range effects.

FDR took great pains to hide the extent of his disability from the public. While the polio virus itself had disappeared and the consequent impairments did not technically make FDR "sick," that was how both he and the American public viewed disability. FDR fit the classic description of an invalid.

The word invalid describes someone who is incapable of caring for themselves. Although illness or sickness is not necessarily a permanent aspect of disability, it is an inherent concept of invalidism. Since no distinction was made between an invalid and a disabled person, that individual was considered to be sick.

FDR refused to let that mistaken perception prevent him from resuming his political career. The course he chose was to convince the American public that he was neither sick nor in-valid, and therefore not disabled in its classic sense. If he could persuade the American public that he was still healthy and vigorous, then they would believe that

FDR could fulfill the duties of public office. To fool the American public into believing that polio had only done minimal physical damage required elaborate, conscious planning, massive assistance, and--from today's vantage-- unbelievable media corroboration.

When FDR appeared in public he did not use his wheelchair. He rose from a seated position using braces and crutches. He was not stable or graceful. Aides held him up creating an illusion that FDR walked without assistance. Crowds "witnessed" FDR walking from his seat to a podium or some other device that he could stand and lean against. Rather than appearing as a sickly invalid, FDR gave the appearance of a healthy politician.

The media supported FDR's efforts to hide the extent of his disability. By conscious yet informal agreement, radio, newspaper and film correspondents simply did not discuss FDR's paralysis. Thirty-five thousand photographs were shot of FDR as President, but only two show him seated in his wheelchair, and these were never published (Hevey 102). This conspiracy of image makers extended as far as political cartoonists who would never draw FDR in his wheelchair, but always standing or walking--or running, or flying!

Although many Americans knew on some level that FDR used a wheelchair, the disguise was so successful that many other Americans professed their ignorance of his disability. As recently as the mid-1990s, this author encountered an individual working at an independent living center who yelped with astonishment upon learning that FDR had a disability. According to Gallagher, this was FDR's "splendid deception" because it enabled him to rise to the Presidency during a time in which everyone was convinced that no one with such a disability could even aspire to that position.

What did FDR's cloaking of his paralysis and wheelchair use mean for people with disabilities? The conclusions are diverse and murky. For many people with disabilities, FDR was a hero, a person who had overcome his disability and acquired the nation's most coveted office. He developed Warm Springs into an international rehabilitation facility. There he drove his car with hand controls that some credit as the first ever designed. Even some people who do not like what FDR did to gain the Presidency believe that he had no choice: given the climate of the times he was forced to hide his disability to succeed politically. Others bemoan his massive cover-up, suggesting this meant that FDR, too, harbored his generation's beliefs about disability meaning illness and invalidism. He was unable to take his own personal situation and generalize it to others in similar circumstances. This, some argue, not only demonstrates FDR's acceptance of disability as illness, but it also contributed to future generations harboring those same beliefs. But, as we will see in the next section, FDR's ambivalence about disability not only affected future generations, but had a significant impact on people who might have been called his peers. (Brown *Investigating* 42-45)

THE LEAGUE OF THE PHYSICALLY HANDICAPPED

The example of the New York League of the Physically Handicapped, rediscovered by historian Paul Longmore in the late 1980s, demonstrates why many people have difficulty portraying FDR as a champion of disability rights. Like Longmore and FDR, most League members had contracted polio, though a few had cerebral palsy, tuberculosis or heart conditions. Unlike FDR, none used wheelchairs. League members came together because they believed they faced discrimination from private industry. They thought that New Deal policies, the name for the programs that FDR spearheaded to combat the Great Depression, would assist their quest for equitable employment. Instead, New Deal programs classified them as "unemployable."

Six League members went to a New York City agency in May of 1935 to discuss these discriminatory policies. When told the individual they wanted to see was out of town, some League members refused to leave. They had not planned to demonstrate, but that is what they did. Three League members remained in the building for nine days. Picketers with and without disabilities supported them outside of the building. Following three weeks of these protests, the group decided to organize formally.

Six months later, in November of 1935, they conducted a three week picket at the New York headquarters of the Works Progress Administration (WPA), one of the primary New Deal agencies for employment. They demanded that, "handicapped people receive a just share of the millions of jobs being given out by the government." As a result, the WPA hired about forty League members. Some skeptical League members believed this action was taken to squash the group, but instead it gained momentum.

In May 1936, a year after their first action, League members traveled to Washington, D.C., to meet with WPA leader Harry Hopkins. When they were informed that he was "away," they voted to stay until "Mr. Hopkins does see us."

Three days later Hopkins did meet with the group. He informed them that he didn't believe there were as many employable New Yorkers with disabilities as the League contended. He also said that he wouldn't change his mind unless he saw an analysis that disproved his belief. Then, he promised, he would take action immediately to correct these conditions.

Several months later, the League presented Hopkins with its "Thesis on Conditions of Physically Handicapped," a ten-page document that offered a comprehensive analysis of the situation. The "Thesis" described job discrimination in private and public sectors and recommended preferential civil-service hiring of disabled veterans and handicapped civilians as well. It also criticized public and private vocational rehabilitation as being underfunded and inadequate. Other employment programs the League critiqued as guilty of worse crimes: sending people to demeaning jobs, including ones as strike-breakers. The League's "Thesis" also accused New Deal programs of ignoring the problems of people with physical disabilities and categorizing people with disabilities as "unemployable."

Betraying his word, Hopkins ignored the "Thesis." The League, dissatisfied with its Washington experiences, renewed its concentration on its New York activities.

In September 1936, the League joined forces with the League for the Advancement of the Deaf to secure a promise that 7% of future WPA jobs in New York would go to deaf and handicapped individuals. As a result, 1500 people went to work. Unfortunately, more than 600 lost their jobs the next spring during nationwide lay-offs.

The League's experiences with New York's WPA was indicative of both its successes and failures. On the positive side, the League did get a number of people jobs and open the public sector to some workers with disabilities. It did not, however, as it had hoped, alter federal policies towards people with disabilities working.

In looking at the history of independent living, the League did not establish a base for future activism. But it did bring to the limelight in the 1930s some issues that would be addressed later in the 1970s and 1980s. League tactics will also seem similar to some current disability protests. Finally, and maybe most importantly, the League identified social problems plaguing people with disabilities that still remain with us.

League picket signs included ones that said, "We Don't Want Tin Cups," and "We Want Jobs." The first could be said to pre-date the current movement against telethons. The second could still be used to protest the current more than 70% unemployment rate of people with disabilities (Longmore and Goldberger 94-98; Longmore, personal communication).

WORLD WAR II VETERANS

Wars always impact disability. If nothing else, wars increase our numbers. There is also often a parallel between war and advances in medicine. An example from World War II (WWII) is that before antibiotics and treatments developed during the war to prevent decubitus ulcers, 80% of those who acquired spinal cord injuries died during the acute phase of their medical care (DeLoach 37).

In the twentieth century, wars have also accelerated disability policies. Both the Paralyzed Veterans of America and the President's Committee on Employment of the Handicapped began shortly after World War II ended. Veterans also benefited after World War II from PL 702, housing legislation passed in 1948 to provide veterans with service-connected disabilities a $10,000 grant in addition to a $10,000 loan to purchase, build, or modify a house (DeLoach 37-38).

Veterans, seeking social reintegration, had significant local impacts. Veterans also had a profound influence on the roots of independent living. In Los Angeles, for example, four WWII veterans began classes at UCLA in 1946 where they were assisted by CAL-VETS, a group of volunteers who carried the vets into inaccessible buildings (DeLoach 37). Our story continues with veterans in the small Midwestern towns of Kalamazoo, Michigan, and Champaign-Urbana, Illinois.

FREEDOM OF MOVEMENT

Jack Fisher was born on September 17, 1918, in Kalamazoo. He learned about the bombing of Pearl Harbor in December 1941 when he was nine months away from graduation at Harvard Law School. Unwilling to continue at Harvard after the bombing, he left school and enlisted in the army. While serving in Oklahoma, he received injuries in a jeep accident in 1943. He was sent from Tinker Field, a US Air Corp Base in the Oklahoma City area, about fifty miles southwest to Borden General Hospital in Chickasha, which housed a special orthopedic unit. Beds there were arranged head to toe so that no one breathed on someone else. The ward he stayed on was for people confined to bed. He remained there from October to February.

For more than four months he roomed with 40 non-ambulatory patients. While lying in a full body cast and traction, he leafed through the medical records of other patients to keep busy. This engrossed him during the day so he could sleep at night. At his discharge in February 1944, Fisher wore steel braces from hips to neck and walked with a pronounced limp.

While continuing to recuperate and learning to live with his residual physical problems, Fisher, at the age of twenty-five, returned to Kalamazoo. He would not return to Harvard Law School while the war waged on. He was determined to obtain a job in a defense industry. While trying to get a job, he kept getting told that with his braces and spastic right leg he could not be used, not even for the lowest possible clerkship. Companies were afraid he'd fall and puncture a lung, risking worker's compensation claims. He was even rejected at Kalamazoo's biggest defense company where he knew the personnel director.

At this point the Disabled American Veterans (DAV) contacted Fisher. The DAV informed Fisher that they needed his help. About five hundred (500) disabled veterans had submitted claims to obtain medical services, financial compensation, wheelchairs, rehabilitation and more. Their files were waiting to be processed. Fisher facilitated hundreds of claims between February 1944 and August 1944 when he finally returned to Harvard Law School.

Fisher graduated from Harvard Law School in February 1945. Large and prestigious eastern firms generally sought Harvard graduates. Fisher's experience was different. Although he had graduated in the top third of his class, he encountered two forms of discrimination. Some firms refused to hire him stating that his disabilities and braces made him a poor risk for health and additional injuries; others would not hire him because he was Jewish.

He decided to begin his own practice. From the first day, disabled veterans whom Fisher had previously assisted retained him as their attorney. He remembers his practice looked like an emergency room, with clients using crutches, wheelchairs and other adaptive equipment. These disabled veterans also brought their parents, grandparents, aunts, uncles, siblings and friends. He worked on all kinds of problems

from purchasing real estate to wills, business ventures, leases, marital concerns and more. Fisher was immersed in the lives of individuals with disabilities as fellow veterans, friends, acquaintances and clients. He learned about the problems of access, mobility, employment, the bedroom and the bathroom.

Fisher journeyed the short distance from Kalamazoo to Percy Jones Hospital in Battle Creek (the old Kellogg sanitorium featured in the movie The Road to Wellville) because it was the official government hospital to treat and rehabilitate amputees. A huge number of both above and below the knee amputees resided in Battle Creek. Many would travel the short distance to Kalamazoo for the bigger city's more active social life. It was not uncommon to see many people using prostheses. Unfortunately for those going downtown, Kalamazoo had quite tall curbs and people would fall on them breaking stumps and injuring themselves. Wheelchair users were simply unable to travel downtown.

In 1945, Fisher took it upon himself to get curb cuts and side-pipe rails. He petitioned the Kalamazoo city commission and testified before them. The city manager, whose adult son used a wheelchair, understood the problem firsthand. The city commission authorized the construction of cement ramps with safety rails in the central business district. Test ramps were constructed in 1945 and placed at the corners of three or four blocks.

A local DAV chapter monitored their usage. In a March 1946 letter to the mayor, Fisher stated that the "ramps were instrumental in allowing disabled veterans, disabled non-veterans, aged and infirm persons and mothers with baby carriages more freedom of movement..." and that "These cement ramps in many instances mean the difference between disabled veterans and disabled non-veterans having employment, as with the ramps a person confined to a wheelchair, on crutches or wearing an artificial limb is able to get to a place of employment unaided. The ramps thus enable many so called unemployable persons to become employable persons, and not only benefit the disabled person alone, but benefit the community at large as well."

Kalamazoo's city commission responded to the experiment by becoming the first city government known to approve a curb cut program, appropriating $680 to install 34 additional curb cuts (Brown, "The Curb Ramps of Kalamazoo").

BUILDING PLANKS TO ROLL ON:
THE GREAT EXPERIMENT AT THE UNIVERSITY OF ILLINOIS

While Jack Fisher worked to implement curb cuts in Kalamazoo, other firsts were taking place in Illinois. In the 1947-48 academic year, a former Veterans Administration Hospital in Galesburg, Illinois, was converted into a satellite campus of the University of Illinois. The University took this action to accommodate the many World War II veterans seeking to utilize the funding of the GI Bill to earn their college degrees.

A year later, however, in 1949, it was decided that the Galesburg campus would be closed. The program's director, Timothy Nugent, appealed unsuccessfully to hundreds of other universities and colleges to adopt the program. There were no takers. Unwilling to accept defeat, Nugent and the students loaded into several cars and set off for the state capitol in Springfield to request that Governor Adlai Stevenson intervene to stop the closure. They staged protests that included building temporary ramps from wooden planks to show how easy it would be to accommodate wheelchairs.

Their effort did not succeed. The campus closed. The students refused to give up. They continued their self-advocacy by seeking to move the "Rehab Program," as they called it, to Champaign-Urbana. Support for the continuation of the program at the main campus was minimal. Most administrators believed that individuals with severe physical disabilities could not possibly live "normal" lives, could not have families and could not obtain gainful employment. Why boost their hopes with a prestigious University of Illinois degree?

The experiment might have ended then except the same group of students with disabilities took their show on the road to Champaign-Urbana. Their goal in traveling to the main campus was to demonstrate that, with minimal architectural and personal assistance, they could successfully negotiate the campus and that they were more than equal to the challenge of the institution's academic programs. After a day of demonstrations, the university begrudgingly granted provisional or "experimental" status to the rehabilitation program at Champaign-Urbana. Attitudes about disability at the university were vehemently expressed. A father of a non-disabled woman dating a post-polio law student despaired that, "I suppose the University should receive some credit for trying to help these poor unfortunates, but isn't there something you can do to protect our sons and daughters from these freaks?" (Expanding Horizons, ii)

The university, wary about the program, limited the number of students that could be admitted--refusing 15 students for every one who got in. For its first eight years the program received no university funding. Nugent drummed up money from outside sources. Students continued to advocate for themselves by demonstrating their abilities through a myriad of activities, research about disability issues and athletic exhibitions ("History of the Division of Rehabilitation").

Campus buildings were not access-friendly. Quonset huts, remaining from World War II, were used as dorms for the first group of students. Campus legend says the huts were

unheated with beds in a row, just like the military. The huts were later converted to house the rehab program's administration offices. They also contained a physical therapy room for students who received credit for physical education classes by participating in PT (Breslin).

After large numbers of people with mobility impairments were admitted, the university ramped buildings and modified the World War II Quonset huts. As new dormitories were built, a limited number of rooms in each building were designed to accommodate students with disabilities. The first floor of most dorms had bathrooms with accessible shower stalls that had aluminum fold down seats and accessible toilet stalls (in the old style--with a door wide enough to face the toilet in the forward position and grab bars). Alumna and contemporary disability advocate Mary Lou Breslin recalls that these dorm rooms were identical to those on the upper floors, which could be reached by elevator in most cases, so the real access was to the first level itself (elevator or ramp) and bathrooms.

The program offered disabled students medical services, physical and occupational therapy, prosthetics, counseling, recreation and a bus service. By the mid-1950s, the Rehabilitation-Education Program (DRES) provided support services and had several lift-equipped buses that made hourly trips around the campus, town and to special university events.

In 1954, a politically savvy group of students with disabilities succeeded in getting Illinois Governor William Stratton to serve as the keynote speaker at the annual disabled students' awards banquet. Although the banquet had not previously been attended by University administrators, the Governor's appearance packed the house. That evening, Governor Stratton gave a stirring speech on the benefits of rehabilitation and the importance of the effort being developed at Illinois. From that point on, although many battles would have to be fought and won in the war for egalitarian access, the program's legitimacy was never again seriously questioned ("History").

The Illinois program expanded to include non-veterans in the 1950s and offered accessible transportation; housing to undergraduate, graduate and married students; peer counseling; specialized medical care; individually designed assistive devices and ADL training (DeLoach 41).

The folklore of the Illinois program is that it equated independence with a physically self-reliant lifestyle. No students could live in university housing if they could not move about campus or had to request help from someone else in self-care activities. Students were required to come to campus early for a week of "functional training." If students could not transfer in and out of bed, dress, bathe and toilet themselves, or maneuver, in their manual wheelchairs, up and down ramps and to the bus stops by themselves in a reasonable amount of time, they were rejected, sent home, invited to practice their skills and reapply. The memory of one student contradicts this well-known folklore. "In fact, some students who couldn't really do these things did occasionally get admitted. One I remember vividly died of complications of muscular dystrophy. I have always thought it

was because he had to struggle so to move about in the freezing weather" (Breslin). Students who successfully completed this training could still be expelled later if they were discovered receiving assistance in their living quarters or being pushed across campus (DeLoach 41-42).

By the early to mid-60s there were about 200 students, with one or two with communication disabilities. "When I was there [there were] several severely disabled students, i.e. high quads or very weak folks with MD who lived in a nearby nursing home, which was then believed to be the only appropriate way to provide personal care for such individuals. Several used power chairs, though the technology was primitive. The obvious point was nursing care was the only answer to not being able to do self care unaided. This practice ended at some point after I graduated" (Breslin).

Perhaps the most popular activities were sports--wheelchair basketball and track, judo for the blind, quadriplegic rugby. Sports, Nugent believed, boosted the athletes' self-confidence and dispelled the notion that disabled students were frail and sickly (Breslin).

Nugent also "was responsible for drafting the first ANSI standards, originally created around the dimension of Everest & Jennings standard push chairs" (Breslin).

Although not as well known in independent living circles as some other university programs, the University of Illinois claims the following firsts:

- The seminal research which led to the development of the first architectural accessibility standards that would become the American National Standards Institute Standards
- The first wheelchair accessible fixed route bus system
- The first accessible university residence halls
- The first university service fraternity and advocacy group comprised of students with disabilities (Delta Sigma Omicron)
- The first collegiate adapted sports and recreation program for students with disabilities, which also produced the first wheelchair athlete in the world to win an Olympic Gold Medal ("History")

With all these advances, why is it that disability advocates tend to recall the University of California as the trailblazer for disability programs? That is the subject of the next section.

POLIO AND THE ED ROBERTS STORY

Veterans inspired the curb cuts of Kalamazoo and the changes in the student population at the University of Illinois. Just as medicine increased the longevity and expanded the activities of veterans wounded in the military, medical progress also had enormous consequences for non-veterans. Medical breakthroughs dramatically affected the polio epidemics of the 1940s and 1950s. Unlike FDR, many of these individuals contracted polio at an early age and did not come from wealthy families.

The polio epidemics of the 1940s and 1950s left about 400 people around the country who both used respirators and were institutionalized. One hundred fifty eight of these individuals were housed at Rancho Los Amigos Medical Center near Los Angeles. The March of Dimes paid their bills, but as that organization became increasingly strapped for funds, they turned over this responsibility to Los Angeles County.

The County, in 1953, conducted a study about attendant care costs. The investigation revealed that each iron lung user would cost the county $10 per day if they lived at home. The hospital billed the state $37 per day for identical services. This discovery led to beginning California's In Home Support Services (IHSS) program, one of the nation's first personal assistance programs (Levy 4-5).

At his home in Burlingame, south of San Francisco, a teenager named Ed Roberts, who had contracted polio and used an iron lung, received IHSS. As he grew older he became credited with breaking the barrier against significantly disabled people attending universities. Roberts has been called the Martin Luther King Jr. of the disability rights movement, the father of independent living. Toward the end of his life, he liked to call himself the godfather. Before Roberts passed away in 1995, he conducted many interviews. Many people also viewed Roberts as one of the best public relations persons in independent living. As a result, quite a bit is known about his life. What follows is his story. It is representative of many others.

Roberts contracted polio when he was in high school. As a result of the virus he lost all but some movement of two fingers on his left hand and two toes on his left foot. The rest of his body, including his lungs, remained paralyzed, though he always retained feeling. Unable to breathe on his own for extended periods, he became a ventilator-dependent quadriplegic. He required a machine, such as an iron lung or a ventilator, to assist him with breathing.

The only person in his school to contract polio, Roberts resumed his education at Burlingame High School at the age of eighteen. He attended via a phone hook-up. It began with a phone connected to one room at the high school. When Ed pressed a bar on the phone he could be heard, when he released the bar he could hear, enabling him not only to listen but to communicate with his classmates.

Roberts graduated from high school, at the age of twenty, in 1959. But not without a fight. His post-polio paralysis prevented him from taking either physical education or

driver's education courses. His high school counselor thought Ed should remain in school another year. Zona, Ed's mother, was determined that her boy would be as similar to his peers as possible and was mystified by this turn of events.

Zona contacted the principal about the inequity of the situation. He supported his counselor. Zona next called a friend who also happened to be a school board member. A school representative met with Zona and Ed at their home and asked, "Ed, you wouldn't like a cheap diploma, would you?" A furious Zona contacted the superintendent of schools. She also notified some of Ed's teachers. Before they could act, the assistant superintendent of schools announced that everyone was proud of Ed and granted the diploma. Roberts later commented that he attained some of his own sense of determination from watching Zona persevere about his graduation.

Ed enrolled at the nearby community College of San Mateo. To attend classes he was placed in a corset which enabled him to sit up. A head brace emerged from the back of the corset. At first, Zona brought Ed to campus. They solicited help from passers-by to get Ed in and out of the car on campus, learning to avoid football player types who refused supervision. Ed attended class by himself, with assistance from fellow students to traverse the numerous steps. Another student was eventually hired to drive Ed.

Roberts spent three years at the College of San Mateo, finishing two years of classwork. To complete assignments, Zona wrote while Ed dictated. Ed speculated about a career as a sportswriter. Others discussed technical writing. He eventually chose political science as a major.

The most fortuitous development at the College of San Mateo occurred in Roberts' second semester when he enrolled in an English class taught by Jean Wirth. Jean, like Ed, knew about difference. She had been six feet, five inches tall from the time she was twelve years old. She became his unofficial advisor.

Jean asked Ed where he wanted to continue his education after graduating from the College of San Mateo. He responded UCLA. Roberts knew about the veterans who had attended and he thought that would make it fairly wheelchair-accessible. Jean dissuaded him from this idea because UCLA was a commuter campus. He would have to find housing, transportation, personal assistance, and friends away from the university. She suggested he apply instead to the University of California at Berkeley (UCB) where there was an outstanding political science program. Ed did just that and was accepted at UCB. The application form asked no questions that related to disability. The only hint was that Ed weighed only eighty-five or ninety pounds. Zona accurately predicted that school officials would guess Ed forgot to put a "1" before the other numerals. Ed also applied to the California Department of Rehabilitation (DR) for financial assistance. The DR counselor informed Ed that he was too severely crippled ever to work and would therefore be denied services. Zona, Jean, and Phil Morse, Ed's official advisor at the College of San Mateo, then met with DR to advocate successfully for Ed.

While this was happening, Jean, Zona, Ed and Phil visited the UCB campus prior to the commencement of the school year. UCB personnel were shocked to learn that Ed was a post- polio ventilator-using quadriplegic and were at a loss about where he might be housed. His large iron lung wouldn't fit in a dorm room. Morse contacted the Dean of Men, who suggested they see Henry Bruyn at Cowell Hospital, the on-campus student health center.

Bruyn, a physician, had worked with polios and commented that they were becoming of college age and should be able to attend college. He thought Ed could probably live at Cowell. Successful negotiations to do just that continued throughout the summer.

During Ed's first academic year, 1962-63, the same year that the African-American James Meredith integrated the University of Mississippi, Ed was the only student with a disability at Cowell, and, as far as we know, the first student with a disability of this significance to attend an American university. An area paper ran a story about Ed headlined "Helpless Cripple Goes to School." It caught the attention of a social worker in nearby Antioch whose client, John Hessler, had broken his neck while diving. Towering above six feet tall, he was too big to be cared for by his parents and he lived in a Contra Costa hospital. He attended Contra Costa College, going back and forth by taxi. His social worker spoke with Henry Bruyn, and John joined Ed at Cowell in the 1963-64 school year.

Bruyn began to earn a reputation for this program. Several more students arrived in 1965-66. Their attendance initiated a formal program for students with disabilities. The students began identifying with one another, calling themselves the Rolling Quads. With a nursing supervisor, the Rolling Quads took over the entire third floor of the hospital. Each student lived in his or her own room. They mingled in a common room and ate together in a dining room.

Ed's DR worker in Berkeley, unlike his geographically-appointed counselor in Burlingame, supported his efforts. DR now paid for tuition, books and secretarial help. This changed again in the late 1960s when DR installed a new worker. She believed it was her responsibility to dictate behavior. She attempted to direct Ed's thesis topic, tried to instruct other students in what classes they could take, and strived to get two students evicted because she didn't approve of their educational goals or lifestyles.

The students responded to this counselor with activism. They informed the press of their frustration with her dictatorial methods and succeeded in getting her transferred. This success led to other actions. The Rolling Quads formally organized themselves into a student organization, and as such they developed and taught a university studies class called "Strategies of Independent Living," the main purpose of which was to conceive methods to live outside of Cowell. They began to talk to the Berkeley city council about building ramps in the city. The Rolling Quads got the city's attention when they went out in the middle of the night with their assistants and started taking sledgehammers to some of the curbs around campus and pouring tar on them to create makeshift ramps.

Some of these still exist today. The Rolling Quads not only tested their own limits as fledgling citizens, they also began to understand their own power.

By the late 1960s, as the Rolling Quads' activism heated up, Roberts prepared to leave Berkeley. He had completed both undergraduate and graduate school, finishing all but his dissertation. Ed accepted a temporary job at the Disabled Student Services program in Riverside, near Los Angeles.

Before Ed moved, Jean Wirth called Zona from Washington to share information about a bill containing a lot of money for disadvantaged students, with ten percent of the budget earmarked for disability programs. Jean suggested Zona come to Washington for meetings about how to utilize the money, but Zona had a scheduling conflict and recommended Jean call Ed. Ed was agreeable and experienced his first airplane flight. Roberts weathered the first of many adventures traveling as an individual with a disability. First, no breathing apparatus was allowed on the plane, so Ed was forced to do exhausting frog-breathing for hours in the air. Then after landing he sat for hours while they retrieved his manual wheelchair. Jean arrived at the hotel before Ed to arrange for an iron lung to be delivered to the hotel. She learned that an iron lung would not be allowed because "they blow up you know."

Despite these hardships, Roberts loved Washington. He reveled in interacting with Senators and Secretaries, and with time's passage he realized that he made a lasting impression.

Since Ed was on his way to his temporary job in Riverside, he urged John Hessler and others to submit a proposal to the old Cabinet Department of Health Education and Welfare (HEW) for funds to institutionalize what they had learned as the Rolling Quads. Their first attempt did not get funded, but their second one did. It became the Physically Disabled Students Program (PDSP).

John Hessler became director of the program. Roberts, meanwhile, did not remain in Riverside long. His physician advised him to leave because the area was harmful to people with breathing problems. He moved to Woodside in the South San Francisco Bay area and began teaching at Nairobi College in East Palo Alto. The college attracted less traditional students than those attending UCB or nearby Stanford.

PDSP began to attract individuals with disabilities from around the San Francisco area. Many callers were not students, but there was nowhere else they could obtain the services they needed. The need to create an organization similar to PDSP for non-students became apparent.

Three people, all of whom had been Rolling Quads, began an organization they called the Center for Independent Living (CIL). A small research and development grant enabled them to rent a small apartment to begin CIL. John Hessler, a CIL board member, quickly became concerned that the much-needed CIL would fail because of a

lack of leadership. He contacted Roberts, who had recently returned to Berkeley from Woodside, about his fears.

Ed and John met with their friends to discuss a CIL board take-over. Their strategy succeeded. Roberts then became CIL director because he did not have a job, while Hessler directed PDSP. Ed expanded CIL rapidly and a national, then international, reputation quickly followed.

When Jerry Brown became governor of California in 1974, three of his former law school classmates, who also happened to be friends of Ed's, nominated Ed to become director of the Department of Rehabilitation (DR). Brown interviewed Ed and appointed him DR director in late 1975. Independent living advocates rarely tire of telling the story of Ed becoming the boss of the agency that had once told him he was "too severely crippled" ever to work. (Brown "Zona and Ed Roberts")

As chief of DR, Roberts soon had the opportunity to institute independent living throughout California. In his first year, $500,000 from the state budget set up eleven independent living programs in the state (Kidder, 10). Shortly thereafter, in the debate over amendments to the Rehabilitation Act in 1978, Roberts was one of many who fought to implement independent living centers in the federal budget.

THE INDEPENDENT LIVING MOVEMENT

Because a comprehensive history of the disability rights and independent living movements is still to be written, the story of Ed Roberts is often discussed as the cornerstone of the independent living movement's origins. But just as Ed's story is a tale of many people, so too is that of the independent living movement. Perhaps most telling is the fact that the same year that CIL in Berkeley began operations, so too did Threshold, an independent living center in Helsinki, Finland. And like CIL, Threshold began first as a student movement. When CIL began in the early 1970s, similar organizations sprouted throughout the United States as well as other parts of the world. For example, a group in Boston began the Boston Center for Independent Living (BCIL). Unlike CIL, BCIL focused on housing issues. BCIL provided housing and attendant services to those college students housed on the fourth floor of the theological college at Boston University, and attendants were recruited from theological students (DeLoach 43). BCIL became formally established in 1974. Other groups formed in Houston, Ann Arbor and many other places across the country and around the world.

This was indeed a movement.

In Washington, D.C., Hugh Gregory Gallagher (long before he authored FDR's Splendid Deception) worked in a congressional office. Gallagher became extremely frustrated in trying to use the inaccessible Library of Congress. He authored the Architectural Barriers Act of 1968, which became the first federal legislation to address architectural accessibility . Unfortunately, it would be years before that kind of thinking and legislation would be enforced. But it's another example of the incipient movement.

How the disability rights movement evolved from "helpless cripples" to a political force includes all of the preceding individuals and actions. In addition, numerous policies have affected disability issues. Perhaps the most important in a history of the independent living movement is the story of Section 504 and the Vocational Rehabilitation program.

"WE WILL ACCEPT NO MORE DISCUSSION OF SEGREGATION"

SECTION 504 AND VOCATIONAL REHABILITATION

Many advocates consider Section 504 of the Rehabilitation Act of 1973 the nucleus of all ensuing progress in obtaining disability rights. Section 504 stated:

> *No otherwise qualified handicapped individual in the United States shall, solely by reason of his handicap, be excluded from the participation in, be denied the benefits of, or be subjected to discrimination under any program or activity receiving federal financial assistance.*

This concise paragraph guaranteed disabled individuals specific civil rights for the first time in history. Vocational rehabilitation, however, began in the early twentieth century. What was its purpose? Why was Section 504 so radical? How come many disability advocates consider Section 504 the opening salvo in the battle for modern disability rights? This section provides a brief history of Vocational Rehabilitation from its beginnings until the early 1970s when the discussion shifts to the campaign to implement Section 504.

Vocational rehabilitation, like many other government programs, did not develop in a vacuum. In fact; it was a culmination of a whirlwind of societal changes.

At the end of the nineteenth century, many community leaders advocated educating all citizens to ensure that the vast numbers of new immigrants understood the civic workings of their new country. Colleges and universities increased in number at the same time. But not everyone now required to obtain an education would attend college. Teaching a manual trade to students who didn't attend college was called vocational education.

While vocational education became part of the landscape of early twentieth century models of education, new medical treatments enabled people with disabling conditions to live longer. Just as medical advances affected post World War II social movements, this earlier medical progress stimulated social change. A new discipline called 'rehabilitation" evolved to work with these individuals.

Rehabilitation's purpose was to find ways to alleviate disabling conditions by keeping people with disabilities in an appropriate social setting. Combining rehabilitation with vocational education led to vocational rehabilitation (Brown *Investigating* 39).

The first laws funding vocational rehabilitation were passed as World War I ended. Congress first passed the Smith-Hughes Law (Vocational Education Act) of 1917, establishing a Federal Board for Vocational Education (FBVE) to work with men with disabilities in hospitals and encampments. The following year Congress unanimously

ratified the Soldier's Rehabilitation Act to assist returning World War I veterans to join the labor pool (Lenihan 51; M. L. Walker 25).

Two years after the Soldier's Rehabilitation Act, President Woodrow Wilson signed the first federal act providing vocational rehabilitation services to civilians with disabilities. The program gave states a choice about participating in it. Most states chose to do so. Just four years after the 1920 passage of the Vocational Rehabilitation Act, thirty-six of the forty-eight states belonged to the program (M. L. Walker 33).

The FBVE, the umbrella agency to which vocational rehabilitation belonged, consisted of the cabinet secretaries of commerce, agriculture and labor as ex-officio members and three salaried members responsible for its operations. John Kratz, vocational rehabilitation (VR) chief in 1924, convinced the FBVE and Congress to renew VR for six years.

Early statistics maintained by VR indicated a modest expenditure of $12,000,000 had rehabilitated 45,000 people between 1921 and 1930. This averaged out to a cost of about $300 per person. By 1930, nine more states participated in the program. A total of 143 rehabilitation workers were employed in 44 states. VR's apparent efficiency led to its renewal in both 1930 and 1932 with increased levels of funding support. Vocational rehabilitation became a permanent program in 1935 (M. L. Walker 39, 58).

In the early thirties, VR transferred to the Office of Education in the Department of the Interior, It did not thrive in this setting. Rehabilitation workers felt their role in placing people with disabilities in the workforce differed from a narrow focus on education. They longed to be housed in another agency. It moved to the Federal Security Agency, created in 1939, along with the Office of Education, but VR continued to be dissatisfied with its place in the hierarchy (M. L. Walker 102-103).

A year later, in 1940, Congress extended vocational rehabilitation services to people with disabilities working in sheltered workshops, those who were homebound, and those in the workforce who required services to remain employed. This significant increase in responsibility set the stage for a decade of greater funding and responsibility. VR grants increased 75% in 1940 and continued to increase throughout the 1940s. In July of 1943, services were broadened to include physical restoration and people with mental illness as clients (Scotch 21; Shapiro 143: M. L. Walker 103).

Vocational Rehabilitation continued to amass larger budgets and greater prestige throughout World War II and the post-war years. Mary Switzer, a career bureaucrat, became director of the agency in 1950. A long-time advocate of vocational rehabilitation's mission, Switzer spent the next two decades zealously expanding its role and power (M. L. Walker 125-26, passim).

Switzer guided a comprehensive legislative package through congressional appropriations in 1954. State vocational rehabilitation grants rose to a budget of $30,000,000. Additional monies for training medical and rehabilitation professionals

established long range agency precedents. Switzer persuaded Congress to fund research and development in medicine and rehabilitation engineering, in-service training programs, rehabilitation centers and sheltered workshops. Switzer also obtained permission to create separate vocational rehabilitation agencies outside of state education agencies (Scotch, 1984, 22).

In the following decade, rehabilitation became a soldier in President Lyndon Johnson's "War on Poverty." Funding levels continued to increase, greater numbers of individuals became eligible to receive services, and state matching fund requirements decreased (M. L. Walker 23).

Mary Switzer reluctantly retired in 1970 when she reached the then-compulsory retirement age of 70 (M L. Walker 253). Her impact has remained legendary within the rehabilitation community. But she might not recognize the evolution of disability rights that occurred after her death a year later.

During Switzer's last years directing VR, organizations like centers for independent living were in their formative stages. Activists with disabilities, like the founders of CIL, empathetic rehabilitation workers, and progressive Congressional colleagues worked together in the early 1970s to implement an agenda for the vocational rehabilitation agency that recognized disability rights. This led to the writing of Section 504.

Sociologist Richard Scotch documented the genesis of Section 504 in his book *From Goodwill to Civil Rights*. He contended that government bureaucrats developed Section 504. But the late John Hessler, who followed Ed Roberts at Cowell and went on to be a founder of PDSP and CIL, disagreed with Scotch's narrative in a letter published in the *Disability Rag*. Hessler remembered a number of activists participating in the concepts and language proposed in the Rehabilitation Act of 1972. According to Hessler's letter, Fred Collignon, a Berkeley community planner who worked with then Rehabilitation Agency Commissioner Ed Newman, actively involved many Berkeley activists in the planning of the early 1970s act. Hessler wrote that he, along with other disability advocates, worked on language that appeared in the eventual act, including the controversial Section 504 (3).

In the Rehabilitation Act of 1972, Hessler and his colleagues across the country thought they had devised a progressive piece of legislation. It included concepts of independent living, client advocacy programs and some prohibitions of discrimination. But President Richard Nixon vetoed the legislation. He predicted that no one had thoroughly assessed the ramifications of the legislation. His own forecast was that parts of the act, like independent living and Section 504, would be extremely costly and become an administrative nightmare.

Nixon's 1972 veto sparked demonstrations across the country. Judy Heumann, who organized disability rights protests in New York City and who had successfully fought being denied a teaching job because she used a wheelchair and who later became the united States Department of Education Assistant Secretary of the Office of Special

Education and Rehabilitative Services, recalled in a 1980 conversation that New York's Disabled in Action organized a demonstration of sixty to eighty people to go to Manhattan's federal building to protest Nixon's 1972 veto. Whey they arrived, they discovered the building was in an isolated section of the city. The demonstrators piled back into their vans and other vehicles, drove to Madison Avenue and stopped traffic on up to four blocks, effectively publicizing their demands (Heumann in "We Won't Go Away...")

In 1973, Congress passed another version of the Rehabilitation Act. This one contained changes Nixon approved, including eliminating independent living and client advocacy programs. But Section 504 remained in the compromise bill. President Nixon signed the Rehabilitation Act of 1973 in September. But more struggles remained (Scotch 56-57).

Section 504, still viewed by disability advocates as the linchpin of change, became bogged down in the Nixon cabinet. HEW expressed the same concerns about costs and administrative headaches that had caused Nixon to veto the earlier bill. The cabinet department simply refused to issue regulations to implement the law.

Frustrated by this federal inaction, James Cherry and the Action League for Physically Handicapped Adults sued the government in 1975 for issuance of 504 regulations. The next year, disabled leaders demonstrated in NEW Secretary David Matthews' office and threatened to picket the 1976 Republican Convention. A federal notice of intent to publish proposed rules materialized in the May 17, 1976 Federal Register. In July of the same year, the courts ruled 504 regulations should be promulgated but did not set a deadline. A second federal notice of intent to publish proposed rules was published in mid-July with little change from the earlier edition (Scotch 93-96); Brown *Investigating* 55-57).

During the 1976 presidential campaign, the Philadelphia contingent of Disabled in Action invited representatives from both major parties to a press conference. The Carter campaign emissary was so totally unaware of disability issues that DIA practically ran her out of the room. She returned to local Carter campaign headquarters and reported how tough DIA had been on her. She then educated herself and convinced the local Carter staff that this was important.

The campaign staff sent her back to talk to the group. Out of that meeting came an effort to organize nationwide for Jimmy Carter. The American Coalition of Citizens with Disabilities (ACCD), which had formed the previous year and with which DIA in Pennsylvania was associated, became the national disability focus of organizing for Carter (Pfeiffer).

Passage of 504 regulations became a battle cry of disability activists throughout the country. Two days after president Jimmy Carter's inauguration in January 1977, about fifteen people met with new HEW Secretary Joseph Califano to advocate for rapid distribution of regulations. The administration received a deadline of April 4, 1977, to issue regulations or disability advocates would pursue an alternative course. Califano

resisted for some of the same reasons that Nixon originally vetoed the entire act. He feared that both actual and administrative costs would be more far reaching than anyone imagined (Eunice Fiorito in "We Won't Go Away....", Scotch 104).

Disability advocates scheduled a series of demonstrations to follow the April 4 deadline. Ten cities across the country were targeted. The most successful action occurred in San Francisco. More than 150 people took over the federal building there and remained for twenty-eight days. Judy Heumann, who had moved to Berkeley to work at CIL in 1973, was one of the event's planners and a leader of the takeover. Ed Roberts, in his new position as director of the California Department of Rehabilitation, did not officially engage in planning the protest but left his Sacramento office to join the protest. Early in the action, Heumann, in a statement reminiscent of freedom fighters of all ages, declared, "...we will no longer allow the government to oppress disabled individuals...we will accept no more discussion of segregation" ("We Won't Go away...").

The protest in San Francisco worked because many in the community supported it. The city's mayor ordered law enforcement personnel to leave the protesters alone. The Black Panthers and the Gray Panthers brought in food donated by Safeway and assisted with personal care needs. Attendants were allowed to go back and forth from the building to bring necessities. This also enabled a communication network with those outside the building to be established (Shapiro 67-68).

Local news stations aired the story. Evan White filed the most comprehensive reports, though he was so new to the field that he did not yet have credentials to file national news stories. But White's luck was good.

Heumann left San Francisco during the occupation to lead a delegation to Washington to talk personally with Califano. He refused to meet with them. They decided to camp on his front lawn until he changed his mind. Evan White traveled from San Francisco to Washington with the group to report the story. A media strike left a void in national news stories, and uncredentialed stringers filed stories. White's coverage of the demonstrations made national news networks and both the story and his career took off (Walker, personal communication).

After twenty-five days of protests, sitting in, and having demonstrators camped on his lawn, Califano signed the 504 regulations. Victorious protesters emerged from the federal building chanting "We Shall Overcome." The siege remains the longest takeover of a federal building by any group in American history (Brown *Investigating* 57-58; Shapiro 69).

A White House Conference on Handicapped Individuals was scheduled to occur May 23-27, 1977. Some speculated one reason Califano signed the regulations was because he knew that 3,000 persons with disabilities and their supporters were on their way to Washington. If he had not signed the regulations by the time they arrived, then

many demonstrations would have occurred to the embarrassment of the Carter administration (Pfeiffer).

The successful protests to implement 504 could be considered the first battle of an ongoing war disability advocates have waged to change vocational rehabilitation. Although hardly the only program affecting disability issues, VR has for many years been perceived as one of the most important influences on disability politics.

FROM BUILDINGS TO STREETS: A GLANCE AT THE LATE 1970s

The disability rights movement accelerated phenomenally in the late 1970s. The scope of this history permits only a glimpse at the people and changes that followed the successful protests for implementation of Section 504.

1977 was the year that Houston's Independent Living Research Utilization (ILRU), the first research organization about independent living, began. ILRU was led by Lex Frieden, one of the significant leaders of that part of the country. Frieden, from northwestern Oklahoma, had been a college freshman at Oklahoma State University in Stillwater when he was involved in a car accident. He became a quadriplegic. After his accident, Frieden began to analyze the roles society had created for people with disabilities--and rebelled against them. At ILRU, Frieden and his colleagues developed a definition of independent living that is still being used: "control over one's life based on the choice of acceptable options that minimize reliance on others in making decisions and in performing everyday activities" (Frieden et al. 3).

One year after the 504 demonstrations and ILRU's founding, another kind of group emerged. ADAPT developed from a radical Denver CIL called the Atlantis Community. Atlantis began when the late Wade Blank, a white veteran of civil rights marches working at a Denver nursing home, rebelled against the oppression he witnessed in that institution. A fictionalized account of Blank's role in the disability movement was highlighted in the 1990 television movie "When You Remember Me," about the fight to remove a young boy with muscular dystrophy from a nursing home to a community-based residence. Blank's role in that action awakened in him a desire to protest the pervasive discrimination against people with disabilities.

One issue of obvious and symbolic importance was transportation. In the 1950s, blacks protested because they had to sit in the back of the bus; but in the 1970s, disabled people protested because they couldn't get on the bus. People who used wheelchairs had no way of entering a bus, even though equipment such as wheelchair lifts was available, comparatively inexpensive and fairly easy to use. A group of nineteen Denver activists organized with Blank to form a group called American Disabled for Accessible Public Transit (ADAPT).

The first ADAPT demonstrations were staged on July 5 and 6, 1978, in Denver. Soon other ADAPT chapters and similar organizations formed throughout the country. Their methods of protest included blocking buses or chaining oneself to a bus so it couldn't move. The theory was that if disabled people could not use the buses then neither could anyone else.

Police quickly arrived to arrest the protesters. But it was not such a simple process. First, police often still thought of disabled people as sick and vulnerable and were either cautious about injuring them or careless about not doing so. Second, the paddy wagons, like the buses, were frequently inaccessible, so police had no way to transfer people to jail. And if they did find a way, the jails were often inaccessible. The protests

continued and ADAPT became the first long- term United States grass roots movement of disability activists (Brown *Investigating* 58-59).

INDEPENDENCE IN THE 1980s AND 1990s

The story of independent living in the past two decades is one of growing pains and what some would term a stormy adolescence. Representative examples are used to describe the history of the past twenty years. A more detailed list of pivotal laws and activism is in Appendix A: Selected Significant Dates in Independent Living History.

During the late 1970s, the first group of federally funded independent living centers feared that in debates surrounding the next reauthorization of the Rehabilitation Act, CILs would be eliminated. Since CILs were still categorized as demonstration projects, not renewing them would be fairly simple. CIL advocates discussed their situation and decided to hold a meeting of all CILs in 1981. From this assembly developed what is now known as the National Council on Independent Living (NCIL). The national organization, first known as the National Council of Independent Living Programs, elected Max Starkloff, founder of Paraquad in St. Louis and former nursing home resident, as its first president. The association then coalesced to ensure that its members retained funding and that they adhered to the independent living philosophy as described at the beginning of this history.

Adhering to this philosophy has not come without battles. Perhaps the most famous of the period occurred in Norman, Oklahoma, when five of six staff members walked out of their CIL because of continuous confrontations with their board, including arguments over consumer control (Brown "The Walkout").

One way to put this conflict into a bigger picture is within the context of models of viewing disability. The one that has most often been called to task within independent living circles is the medical model.

Medicine, like all disciplines, has its method. A physician is trained to detect symptoms, diagnose ailments and prescribe cures. A person with a disability is not sick. A disabled person may become ill with a cold, or flu, or measles, or any other ailment a nondisabled person might acquire. But having a disability is not the same as being perpetually indisposed. There are many healthy quadriplegics. There are also sickly quadriplegics. But the quadriplegia itself is simply an inability to use all or part of four limbs. It is a disability; it is not an illness.

Medical personnel are not trained to appreciate this distinction. They are instructed to cure illnesses. When that is not possible, as in the case of disability, medical training is inadequate. Medical solutions to disability issues have been called a medical model. This model is distinguished by perpetuating the notion that someone who has a disability is broken, in disrepair, or infirm. This perception is easily integrated into medical training. If patients are broken, they can be fixed. If ill, they can be cured. There is only one viable alternative to this philosophy, and that is death. There is no room for any intermediate position. Ongoing disability does not enter into the equation.

In the medical model, if people can neither be fixed nor cured and will not die, then they are no longer of medical concern, other than easing the inevitable wait for departure from this world. The medical model validates previous perceptions of incompetence, deviance, and invalidism. Individuals with disabilities have no worth in either the medical or the social hierarchy. As one might imagine, this philosophy leads to confrontation with the notion of capable, valuable human beings with disabilities put forth by advocates with disabilities (Brown *Investigating* 52-53).

In the confrontation in Norman, the fallout from the medical model was apparent. People without disabilities felt a need to tell people with disabilities how to run their organization and, by extension, their lives. People with disabilities who were learning to rebel against models that had invalidated their own choices responded defiantly.

This led to a change in the last revision of the Rehabilitation Act in the 1980s. Known as consumer control, this change requires that more than half of the members of the board of directors in each center for independent living must be individuals with disabilities. In the 1990s this was expanded to include CIL management as well.

As independent living centers not only remained in the Rehabilitation Act but increased in numbers and funding, NCIL gained momentum throughout the 1980s. During the latter part of the decade, Marca Bristo, disability rights activist and executive director of Access Living in Chicago, who in the Clinton years has chaired the National Council on Disability, became the organization's president. She led a fight against what some observers saw as a Ronald Reagan supported backlash against progress for individuals with disabilities. Reagan unsuccessfully attempted to overturn Section 504. But Reagan is not easy to dismiss simply as an anti-disability leader. He also appointed Lex Frieden to direct the National Council on the Handicapped (now National Council on Disability) and Justin Dart as commissioner of the Rehabilitation Services Administra-tion. Each of these individuals became pivotal in advancing our rights. While Frieden, Dart and others worked with the Reagan administration, Bristo's leadership and fiery orations guided demonstrators into opposition protest marches.

One of the most detrimental decisions of the 1980s came from the Supreme Court, which ruled in the mid-1980s that 504 applied only to the part of an institution that directly received federal funds. This meant that entire universities, for example, did not have to comply with Section 504, only that part of the school that put federal funds in its program's budget. Disability advocates fought for several years to negate this ruling, and in 1988 Congress passed, over Reagan's veto, the Civil Rights Restoration Act which ensured that "Federal anti-discrimination statutes apply to an institution in its entirety if it accepts Federal aid for as little as one program" (Levy 34).

While advocates fought to restore the intent of 504, Lex Frieden led a study at the National Council on the Handicapped about the place of people with disabilities in American society. Published in 1986 as Toward Independence, the monograph described discriminatory policies towards people with disabilities in housing, employment, transportation, education and other aspects of American life. It called for

the passage of a law which would bar such discrimination. This led advocates to draft legislation that eventually became the 1990 Americans with Disabilities Act (ADA).

One of the national stories that helped convince Congress to pass the ADA occurred in 1988 at Gallaudet University--the world's only university for students who are deaf and hard of hearing. In 1987, Gallaudet's president announced his resignation. Early the next year, several Gallaudet students concurred that the time was right for the university to select its first deaf president. The Gallaudet board of trustees ignored the students and chose the only hearing person of three candidates. The deaf student population rebelled with what became known as the Deaf President Now movement. Taking their issues to both the national media and to Congress, the Deaf President Now movement quickly amassed national support. In a matter of one week, the Gallaudet board agreed to the student demands, hiring popular and deaf Gallaudet dean of arts and sciences I. King Jordan as president. They also changed the composition of the board of trustees to half deaf (Shapiro 75-83).

The injustice of a hearing person trying to run a deaf university struck a chord with both the American people and Congress and helped both to understand why people with disabilities would want a law like ADA. It was one of many stories that helped achieve passage of what has been called the most important civil rights law since the Civil Rights Act of 1964.

Personal stories often embrace solutions to much larger matters. Autobiography, in fact, often plays vital roles in the passage of laws. This situation occurred with the fight to pass the Americans with Disabilities Act of 1990 (ADA).

Justin Dart, a longtime disability advocate, spent a considerable amount of time and money traveling to every state in the union in the late 1980s to collect information demonstrating the need for the ADA. He asked people to write or relate discrimination diaries, experiences that people with disabilities had in their everyday lives that led to their belief in the desirability of a such a law.

Many stories were collected. Some of the more poignant storytellers testified before Congress. One was a young woman from the state of Washington who has cerebral palsy. She testified that she tried to get into her hometown theater to see a movie, but the ticket taker would not admit her because her speech was slurred. This woman's story touched the heart of many members of Congress and President Bush, who recounted it when greeting celebrants at the ADA signing (Brown, *Investigating* 74; Shapiro 105-06, 140).

The ADA was not passed without many confrontations. ADAPT led a march on the Capitol steps in which people abandoned their wheelchairs and crawled up to the entryway to Congress. On the second anniversary of the signing of the ADA in 1992, Denver dedicated a plaque to the first ADAPT activists of the late 1970s. Wade Blank, as a nondisabled person, didn't believe his name belonged on the plaque, but he did

visit it once a week to clean it of bird droppings and other debris (Hartman, personal communication).

During the remainder of the 1990s, independent living advocates have fought to solidify their gains, expand independent living centers, retain the intent of the ADA in court decisions, get people who do not want to languish in nursing homes out into the community and fight the trend toward passage of assisted suicide legislation.

INDEPENDENT LIVING IN THE YEAR 2000

From the institutionalization of independent living centers to the current court cases that are redefining the meaning of ADA, the independent living movement has been an incredibly active part of our nation's late twentieth century history. There are now more than 600 centers in existence in every state and many countries. What can we expect at the dawn of the next millennium? Here are some highlights:

- More and more disabling conditions will be recognized as important to the independent living movement, such as people with psychiatric disabilities, mental retardation, multiple chemical sensitivities, AIDS and new conditions that arise.
- The recognition among more people with disabilities and the mainstream population that there is such a thing as Disability Culture, the movement by people with disabilities to infuse our own experiences into all aspects of everyday life, as most easily seen now in books, movies, music and other expressions of art.
- The importance of persuading the mainstream media to understand our issues from our perspective.
- The national organizing for the Spirit of ADA to celebrate our lives and victories from the last twenty-five years, culminating with events around the country on or about July 26, 2000, the tenth anniversary of the signing of the ADA.
- A comprehensive history of our movement and its importance written by one of us!

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APPENDIX A

SELECTED SIGNIFICANT DATES IN INDEPENDENT LIVING HISTORY

(for a more comprehensive list see: http://www.sfsu.edu/~hrdpu/chron.htm)

1918: The Smith-Sears Veterans Vocational Rehabilitation Act establishes a federal vocational rehabilitation program for disabled soldiers.

1920: The Fess-Smith Civilian Vocational Rehabilitation Act is passed, creating a vocational rehabilitation program for disabled civilians.

1921: The American Foundation for the Blind is founded.

1927: Franklin Roosevelt co-founds the Warm Springs Foundation at Warm Springs, Georgia.

The U.S. Supreme Court, in Buck v. Bell, rules that the forced sterilization of people with disabilities is not a violation of their constitutional rights.

1929: Seeing Eye establishes the first dog guide school for blind people in the United States.

1932: Disabled American Veterans is chartered by Congress to represent disabled veterans in their dealings with the federal government.

1933: Franklin Delano Roosevelt, the first seriously physically disabled person ever to be elected as a head of government, is sworn into office as president of the United States.

1936: Passage of the Randolph Sheppard Act establishes a federal program for employing blind vendors at stands in the lobbies of federal office buildings.

1937: Herbert A. Everest and Harry C. Jennings patent a design for a folding wheelchair with an X-frame that can be packed into a car trunk.

1940: The National Federation of the Blind is formed in Wilkes-Barre, Pennsylvania, by Jacobus tenBroek and other blind advocates.

The American Federation of the Physically Handicapped is founded by Paul Strachan as the nation's first cross-disability, national political organization.

1944: Howard Rusk is assigned to the U.S. Army Air Force Convalescent Center in Pawling, New York, where he begins a rehabilitation program for disabled

airmen. First dubbed "Rusk's Folly" by the medical establishment, rehabilitation medicine becomes a new medical specialty.

1945: President Harry Truman signs a joint congressional resolution calling for the creation of an annual National Employ the Handicapped Week.

1956: Accent on Living begins publication.

1958: Gini Laurie becomes editor of the Toomeyville Gazette at the Toomey Pavilion Polio Rehabilitation Center. Eventually renamed the Rehabilitation Gazette, this grassroots publication becomes an early voice for disability rights.

1960: The first Paralympic Games, under the auspices of the International Paralympic Committee (IPC), are held in Rome, Italy.

1961: The American Council of the Blind is formally organized.

The American National Standards Institute, Inc. (ANSI) publishes American Standard Specifications for Making Buildings Accessible to, and Usable by, the Physically Handicapped.

1962: Edward V. Roberts becomes the first severely disabled student at the University of California at Berkeley.

1963: South Carolina passes the first statewide architectural access code.

1964: Robert H. Weitbrecht invents the "acoustic coupler," enabling teletypewriter messages to be sent via standard telephone lines. This invention makes possible the widespread use of teletypewriters for the deaf.

1968: The Architectural Barriers Act is passed, mandating that federally constructed buildings and facilities be accessible to people with physical disabilities. This act is generally considered to be the first ever federal disability rights legislation.

1970: Nursing home resident Max Starkloff founds Paraquad in St Louis.

Disabled in Action is founded in New York City by Judith Heumann, after her successful employment discrimination suit against the city's public school system.

The Physically Disabled Students Program (PDSP) is founded by Ed Roberts, John Hessler, Hale Zukas and others at the University of California at Berkeley.

Congress passes the Urban Mass Transportation Assistance Act, declaring it a "national policy that elderly and handicapped persons have the same right as

other persons to utilize mass transportation facilities and services." The law contains no provision for enforcement.

1971: The National Center for Law and the Handicapped is founded at the University of Notre Dame in South Bend, Indiana, becoming the first legal advocacy center for people with disabilities in the United States.

1972: The Center for Independent Living (CIL) is founded in Berkeley, California.

The Houston Cooperative Living Residential Project is established in Houston, Texas.

1973: The first handicap parking stickers are introduced in Washington, D.C.

The Architectural and Transportation Barriers Compliance Board is established under the Rehabilitation Act of 1973 to enforce the Architectural Barriers Act of 1968.

1974: *Halderman v. Pennhurst* is filed in Pennsylvania on behalf of the residents of the Pennhurst State School Hospital. The case, highlighting the horrific conditions at state "schools" for people with mental retardation, becomes an important precedent in the battle for deinstitutionalization, establishing a right to community services for people with developmental disabilities.

The first convention of People First is held in Salem, Oregon. People First becomes the largest U.S. organization composed of and led by people with cognitive disabilities.

North Carolina passes a statewide building code with stringent access requirements drafted by access advocate Ronald Mace. This code becomes a model for effective architectural access legislation in other states. Mace founds Barrier Free Environments to advocate for accessibility in buildings and products.

1975: Congress passes the Developmentally Disabled Assistance and Bill of Rights Act, providing federal funds to programs serving people with developmental disabilities and outlining a series of rights for those who are institutionalized. The lack of an enforcement mechanism within the bill and subsequent court decisions will, however, render this portion of the act virtually useless to disability rights advocates.

The Education for All Handicapped Children Act (Pub. Law 94-142) is passed, establishing the right of children with disabilities to a public school education in an integrated environment. The act is a cornerstone of federal disability rights legislation. In the next two decades, millions of disabled children will be educated under its provisions, radically changing the lives of people in the disability community.

The American Coalition of Citizens with Disabilities is founded. It becomes the preeminent national cross-disability rights organization of the 1970s.

The Association of Persons with Severe Handicaps (TASH) is founded by special education professionals responding to *PARC v. Pennsylvania* (1972) and subsequent right-to-education cases. The organization will eventually call for the end of aversive behavior modification and the closing of all residential institutions for people with disabilities.

The Atlantis Community is founded in Denver as a group housing program for severely disabled adults who, until that time, had been forced to live in nursing homes.

Mainstream: Magazine of the Able-Disabled begins publication in San Diego.

Edward Roberts becomes the director of the California Department of Rehabilitation. He moves to establish nine independent living centers across that state, based on the model of the original Center for Independent Living in Berkeley. The success of these centers demonstrates that independent living can be replicated and eventually results in the founding of hundreds of independent living centers all over the world.

1976: Passage of an amendment to Higher Education Act of 1972 provides services to physically disabled students entering college.

The Disability Rights Center is founded in Washington, D.C. Sponsored by Ralph Nader's Center for the Study of Responsive Law, it specializes in consumer protection for people with disabilities.

1977: President Jimmy Carter appoints Max Cleland to head the U.S. Veterans Administration, making Cleland the first severely disabled (as well as the youngest) person to fill that position.

The White House Conference on Handicapped Individuals brings together 3,000 disabled people to discuss federal policy toward people with disabilities. This first ever gathering of its kind results in numerous recommendations and acts as a catalyst for grassroots disability rights organizing.

Passage of the Legal Services Corporation Act Amendments adds financially needy people with disabilities to the list of those eligible for publicly funded legal services.

1978: Disability rights activists in Denver stage a sit-in demonstration, blocking several Denver Regional Transit Authority buses to protest the complete inaccessibility of that city's mass transit system.

Title VII of the Rehabilitation Act Amendments of 1978 establishes the first federal funding for independent living and creates the National Council of the Handicapped under the U.S. Department of Education.

On Our Own: Patient Controlled Alternatives to the Mental Health System is published. Written by Judi Chamberlin, it becomes a standard text of the psychiatric survivor movement.

1979: Funding of the first ten independent living centers funded through the Rehabilitation Act.

The U.S. Supreme Court, in *Southeastern Community College v. Davis*, rules that, under Section 504 of the Rehabilitation Act of 1973, programs receiving federal funds must make "reasonable modifications" to enable the participation of otherwise qualified disabled individuals. This decision is the Court's first ruling on Section 504, and it establishes reasonable modification as an important principle in disability rights law.

Marilyn Hamilton, Jim Okamoto and Don Helman produce their "Quickie" lightweight folding wheelchair, revolutionizing manual wheelchair design.

The Disability Rights Education and Defense Fund (DREDF) is founded in Berkeley, California, becoming the nation's preeminent disability rights legal advocacy center and participating in much of the landmark litigation and lobbying of the 1980s and 1990s.

Self Help for Hard of Hearing People, Inc., is founded in Bethesda, Maryland, by Howard "Rocky" Stone.

1980: The first issue of the *Disability Rag* (now *Ragged Edge*) is published in Louisville, Kentucky.

Disabled Peoples' International is founded in Singapore, with the participation of advocates from Canada and the United States.

1981: The International Year of Disabled Persons begins with speeches before the United Nations General Assembly. During the year, governments are encouraged to sponsor programs bringing people with disabilities into the mainstream of their societies.

In an editorial in the *New York Times*, Evan Kemp, Jr., attacks the Jerry Lewis National Muscular Dystrophy Association Telethon, writing that "the very human desire for cures can never justify a television show that reinforces a stigma against disabled people."

1981-1984: The parents of "Baby Doe" in Bloomington, Indiana, are advised by their doctors to deny a surgical procedure to unblock their newborn's esophagus because the baby has Down syndrome. Although disability rights activists try to intervene, Baby Doe starves to death before legal action can be taken. The case prompts the Reagan administration to issue regulations calling for the creation of "Baby Doe squads" to safeguard the civil rights of disabled newborns.

The Telecommunications for the Disabled Act mandates telephone access for deaf and hard-of-hearing people at important public places, such as hospitals and police stations, and that all coin-operated phones be hearing aid-compatible by January 1985. It also calls for state subsidies for production and distribution of TDDs (telecommunications devices for the deaf), more commonly referred to as TTYs.

The National Council on Independent Living is formed to advocate on behalf of independent living centers and the independent living movement.

1983: The Disabled Children's Computer Group (DCCG) is founded in Berkeley, California.

Ed Roberts, Judy Heumann and Joan Leon found the World Institute on Disability in Oakland, California.

American Disabled for Accessible Public Transit (ADAPT) is organized at the Atlantis Community headquarters in Denver, Colorado. For the next seven years ADAPT conducts a civil disobedience campaign against the American Public Transit Association (APTA) and various local public transit authorities to protest the lack of accessible public transportation.

The United Nations expands the International Year of Disabled Persons into the International Decade of Disabled Persons, to last from 1983 to 1992.

1984: George Murray becomes the first wheelchair athlete to be featured on the Wheaties cereal box.

The Voting Accessibility for the Elderly and Handicapped Act mandates that polling places be accessible or that ways be found to enable elderly and disabled people to exercise their right to vote. Advocates find that the act is difficult, if not impossible, to enforce.

1985: Wry Crips, a radical disability theatre group, is founded in California.

The U.S. Supreme Court rules, in *City of Cleburne v. Cleburne Living Center*, that localities cannot use zoning laws to prohibit group homes for people with developmental disabilities from opening in a residential area solely because its residents are disabled.

The National Association of Psychiatric Survivors is founded.

Mental Illness Bill of Rights Act is passed.

1986: The Air Carrier Access Act is passed, prohibiting airlines from refusing to serve people simply because they are disabled and from charging them more for airfare than non-disabled travelers.

The National Council on the Handicapped issues *Toward Independence*, a report outlining the legal status of Americans with disabilities, documenting the existence of discrimination and citing the need for federal civil rights legislation (what will eventually be passed as the Americans with Disabilities Act of 1990).

Concrete Change, a grassroots organization advocating for accessible housing, is organized in Atlanta, Georgia. The Protection and Advocacy for Mentally Ill

Individuals Act is passed, setting up protection and advocacy agencies for people who are in-patients or residents of mental health facilities.

The Society for Disability Studies is founded.

The Rehabilitation Act Amendments of 1986 define supported employment as a "legitimate rehabilitation outcome."

1987: Marlee Matlin wins an Oscar for her performance in Children of a Lesser God.

The AXIS Dance Troupe is founded in Oakland, California.

The US. Supreme Court, in *School Board of Nassau County, Fla. v. Arline*, outlines the rights of people with contagious diseases under Title V of the Rehabilitation Act of 1973. It establishes that people with infectious diseases cannot be fired from their jobs "because of prejudiced attitude or ignorance of others."

1988: Students at Gallaudet University in Washington, D.C., organize a week-long shut-down and occupation of their campus to demand selection of a deaf president after the Gallaudet board of trustees appoints a non-deaf person as president of the university. On March 13, the Gallaudet administration announces that I. King Jordan will be the university's first deaf president.

The Technology-Related Assistance Act for Individuals with Disabilities is passed, authorizing federal funding to state projects designed to facilitate access to assistive technology.

The Fair Housing Amendments Act adds people with disabilities to those groups protected by federal fair housing legislation and establishes minimum standards of adaptability for newly constructed multiple-dwelling housing.

Congress overturns President Ronald Reagan's veto of the Civil Rights Restoration Act of 1987. The act undoes the Supreme Court decision in *Grove City v. Bell* and other decisions limiting the scope of federal civil rights law, including Section 504 of the Rehabilitation Act of 1973.

1989: The Center for Universal Design (originally the Center for Accessible Housing) is founded by Ronald Mace in Raleigh, North Carolina.

Mouth: The Voice of Disability Rights begins publication in Rochester, New York.

1990: The Americans with Disabilities Act is signed by President George Bush on July 26 in a ceremony on the White House lawn witnessed by thousands of disability rights activists. The law is the most sweeping disability rights legislation in history, for the first time bringing full legal citizenship to Americans with disabilities. It mandates that local, state, and federal governments and programs be accessible, that businesses with more than 15 employees make "reasonable accommodations" for disabled workers, that public accommodations such as restaurants and stores make "reasonable modifications" to ensure access for disabled members of the public. The act also mandates access in public transportation, communication and other areas of public life.

The Ryan White Comprehensive AIDS Resources Emergency Act is passed to help localities cope with the burgeoning HIV/AIDS epidemic.

With passage of the Americans with Disabilities Act, American Disabled for Accessible Public Transit (ADAPT) changes its focus to advocating for personal assistance services and changes its name to American Disabled for Attendant Programs Today.

The Education for All Handicapped Children Act is amended and renamed the Individuals with Disabilities Education Act (IDEA).

1991: Jerry's Orphans stages its first annual picket of the Jerry Lewis Muscular Dystrophy Association Telethon.

1993: Robert Williams becomes commissioner of the Administration on Developmental Disabilities, the first developmentally disabled person to hold that post.

1995: Justice for All is founded in Washington, D.C.

When Billy Broke His Head... and Other Tale of Wonder premiers on PBS. The film is, for many, an introduction to the concept of disability rights and the disability rights movement.

The American Association of People with Disabilities is founded in Washington, D.C.

The U.S. Court of Appeals for the Third Circuit, in *Helen L. v. Snider*, rules that the continued publicly funded institutionalization of a disabled Pennsylvania woman in a nursing home, when not medically necessary and where the state of Pennsylvania could offer her the option of home care, is a violation of her rights under the Americans with Disabilities Act of 1990.

Sandra Jensen, a member of People First, is denied a heart-lung transplant by the Stanford University School of Medicine because she has Down syndrome. After pressure from disability rights activists, administrators there reverse their decision, and, in January 1996, Jensen becomes the first person with Down syndrome to receive a heart-lung transplant.

1996: Not Dead Yet is formed by disabled advocates to oppose Jack Kevorkian and the proponents of assisted suicide for people with disabilities.

Sen. Robert Dole becomes the first person with a visible disability since Franklin Roosevelt to run for president of the United States. Unlike Roosevelt, he publicly acknowledges the extent of his disability. He is defeated by incumbent Bill Clinton.

Disabled Persons' Independence Movement--Oral History of the Berkeley Movement is funded by the National Institute on Disability Research and Rehabilitation.

1999: Jack Kevorkian is sentenced for murder. He has been a proponent for and a practitioner of what is called "physician-assisted suicide."

About 50 disability advocates gathered in Louisville, KY, to discuss methods to bring disability issues more effectively to the media at the 1999 May Media Meeting.

Very Special Arts changes its name to VSA Arts.

Groups from all over the United States are planning Spirit of ADA, to celebrate the 10th anniversary of the signing of the ADA, 25th anniversary of IDEA, 25th anniversary of the American Coalition of Citizens with Disabilities (ACCD) and the 50th anniversary of Arc.

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IL 201 – History & Philosophy of the Independent Living Movement

August 8, 2002

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IL NET Presents

Teleconference:

IL 201 – History & Philosophy of the Independent Living Movement

August 8, 2002

Participants List

Ohio

Ability Center of Greater Toledo
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Number of Participants: 8
Voice: 419-885-5733
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Ohio

The Ability Center
516 Perry Street
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Site Coordinator: Kristina Noe
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Pennsylvania

CIL of South Central PA
9th Avenue & 17th
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Pennsylvania

Tri-County Patriots for Independent Living
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Pennsylvania

NE PA Center for Independent Living
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Pennsylvania

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Pennsylvania

Liberty Resources Inc.
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Philadelphia, PA 19125
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South Dakota

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South Dakota

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Tennessee

CIL of Middle Tennessee
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Tennessee

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Texas

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Texas

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Utah

OPTIONS for Independence
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Virginia

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Wisconsin

Midstate Independence Living Consultants
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Site Coordinator: **Kristin Luchterhand**
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Wisconsin

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IL 201 – HISTORY & PHILOSOPHY OF THE INDEPENDENT LIVING MOVEMENT

August 8, 2002

Teleconference Evaluation Form

WE VALUE YOUR OPINION! We review every evaluation form. Please give us your feedback about today's program by completing this form and mailing it back to: National Council on Independent Living; Att: Toony Buppapong; 1916 Wilson Blvd., Ste. 209; Arlington, VA 22201.

	Not at all		Average		Excellent
Was the teleconference content:					
Organized?	1	2	3	4	5
Interesting?	1	2	3	4	5
Useful?	1	2	3	4	5
What you hoped it would be?	1	2	3	4	5
Overall content rating	1	2	3	4	5
How well did the trainer know the subject?					
Julia Sain	1	2	3	4	5
How well did the trainer hold your attention?					
Julia Sain	1	2	3	4	5
How relevant were the trainer's examples?					
Julia Sain	1	2	3	4	5
Please rate the following overall:	**Poor**		**Average**		**Excellent**
Overall rating – Julia Sain	1	2	3	4	5
Overall conference rating	1	2	3	4	5

How likely is it that you will use what you learned at this training?	Low 1	2	3	4	High 5

How well did this training develop your skills and knowledge for...

	Low				High
1. the IL philosophy of consumer control and peer relationships as it was taught by IL founding fathers and mothers?	1	2	3	4	5
2. some of the major characters and the defining moments of their lives?	1	2	3	4	5
3. how the first Center for Independent Living was established and how its design shaped the future of the Rehabilitation Act?	1	2	3	4	5
4. having insight into the evolution of the "system" that now governs the nature of CILs and SILCs?	1	2	3	4	5

Please list 2 or 3 of the most important things you learned from this training.

What else do you wish you would have learned at this training?

What do you wish the training had spent more time on?

What do you wish the training had spent less time on?

What might prevent you from using the information on the job?

What would you like to see IL NET do as an on-site training?

What would you like to see IL NET do as a teleconference?

We appreciate any comments you can make that will help us do a better job:

IL NET TRAINING PROJECT

Teleconference:
IL 201 – History & Philosophy of the Independent Living Movement

Site Evaluation Form

On a scale from 1 (the lowest rating) to 4 (the highest rating), please rate your Site.

1. Did the Site Coordinator prepare the manual in the format that is accessible for you?

   Yes No N/A

   Comment:

2. Were you given page numbers in your format to correspond with regular print?

   Yes No N/A

   Comment:

3. Did you receive the training manual prior to the teleconference?

   Yes No N/A

   Comment:

4. Were you asked to participate in the Pre-Conference?

Yes No N/A

Comment:

5. How useful was the Pre-Conference?

1 (Low) 2 3 4 (High)

6. Were you asked to participate in the Post-Conference?

Yes No N/A

Comment:

7. How useful was the Post-Conference?

1 (Low) 2 3 4 (High)

8. Were you provided with a participants list and evaluation in a format accessible to you?

Yes No N/A

Comment:

9. Did the phone used for the teleconference have a clear connection?

Yes No N/A

Comment:

10. Did your Site Coordinator, make the teleconference accessible for you, i.e. real time captioning, interpreters, assistive listening device etc.,?

Yes No N/A

Comment:

11. What would you like to see as in-service provided by your Site?

Site Coordinators this evaluation is for your records to enhance your sites learning experience.

Please return all forms to your Site Coordinator.

IL NET Presents

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Do-It-Yourself Kit

A Do-It-Yourself Kit of the **IL NET** National Teleconference is available. If you would like a Kit, please fill out the order form below.

Please Print or Type

Name: _____

Center: _____

Address: _____

Telephone: _____ Fax: _____

Number of sets: _____ x $125.00 = $_____
(shipping included)

Payment Information:

Credit Card#_____ **Exp.**_____

Print Name:_____

Authorizing Signature:_____
(By signing you authorize NCIL to charge the Kit to your credit card) Visa and MasterCard only.

Please mail order form and payment to :
National Council on Independent Living
1916 Wilson Blvd., Suite 209
Arlington, VA 22201
Attention: Toony Buppapong

IL NET Presents

IL 201 – History & Philosophy of the Independent Living Movement

August 8, 2002

Audio Tape Order Form

An audio cassette of the **IL NET** National Teleconference training is available. If you would like a copy, please fill out the order form below.

Please Print or Type

Name: _____

Center: _____

Address: _____

Telephone: _____ Fax: _____

Number of sets: _____ x $25.00 = $_____
(shipping included)

Payment Information:

Credit Card#_____ **Exp.**_____

Print Name:_____

Authorizing Signature:_____
(By signing you authorize NCIL to charge the Audio Tape to your credit card) Visa and MasterCard only.

Please mail order form and payment to :
National Council on Independent Living
1916 Wilson Blvd., Suite 209
Arlington, VA 22201
Attention: Toony Buppapong

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